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ABSTRACT

A national conference on autism, attended by agency staff, organization staff, advocates, and parents of children and adults with autism, consisted of paper presentations, site visits, and small group reports and recommendations. This volume of proceedings includes papers with the following authors and titles: (1) "An Overview of the Rehabilitation of Persons with Autism" (A. M. Donnellan); (2) "New Concepts of Autism and Related Disorders" (M. B. Denckla); (3) "The Vocational Rehabilitation System" (P. Griswold); (4) "Critical Dimensions of Non-Sheltered Employment Models" (M. D. Smith); (5) "A Supported Work Approach to Competitive Employment of Individuals with Moderate and Severe Handicaps" (J. Hill); (6) "Staff Development and Training" (G. Mesibov); (7) "Legislative, Regulatory and Financial Issues Affecting the Rehabilitation and Vocational Achievement of Persons with Autism" (F. Laski); and (8) "Autism Services: A Blueprint for the Future" (D. Fenderson). Small group reports present recommendations about legislative, regulatory, and financial issues related to the provision of vocational rehabilitation services to persons with autism (Group I); nonsheltered employment models (Group II); adult service systems (Group III); and rehabilitation personnel preparation regarding autism (Group IV). Appendixes present an overview of the Community Services for Autistic Adults and Children Vocational Program and lists of members of the Autism Program Planning Committee, sponsors, coordinators, conference faculty, and conference participants. (CB)

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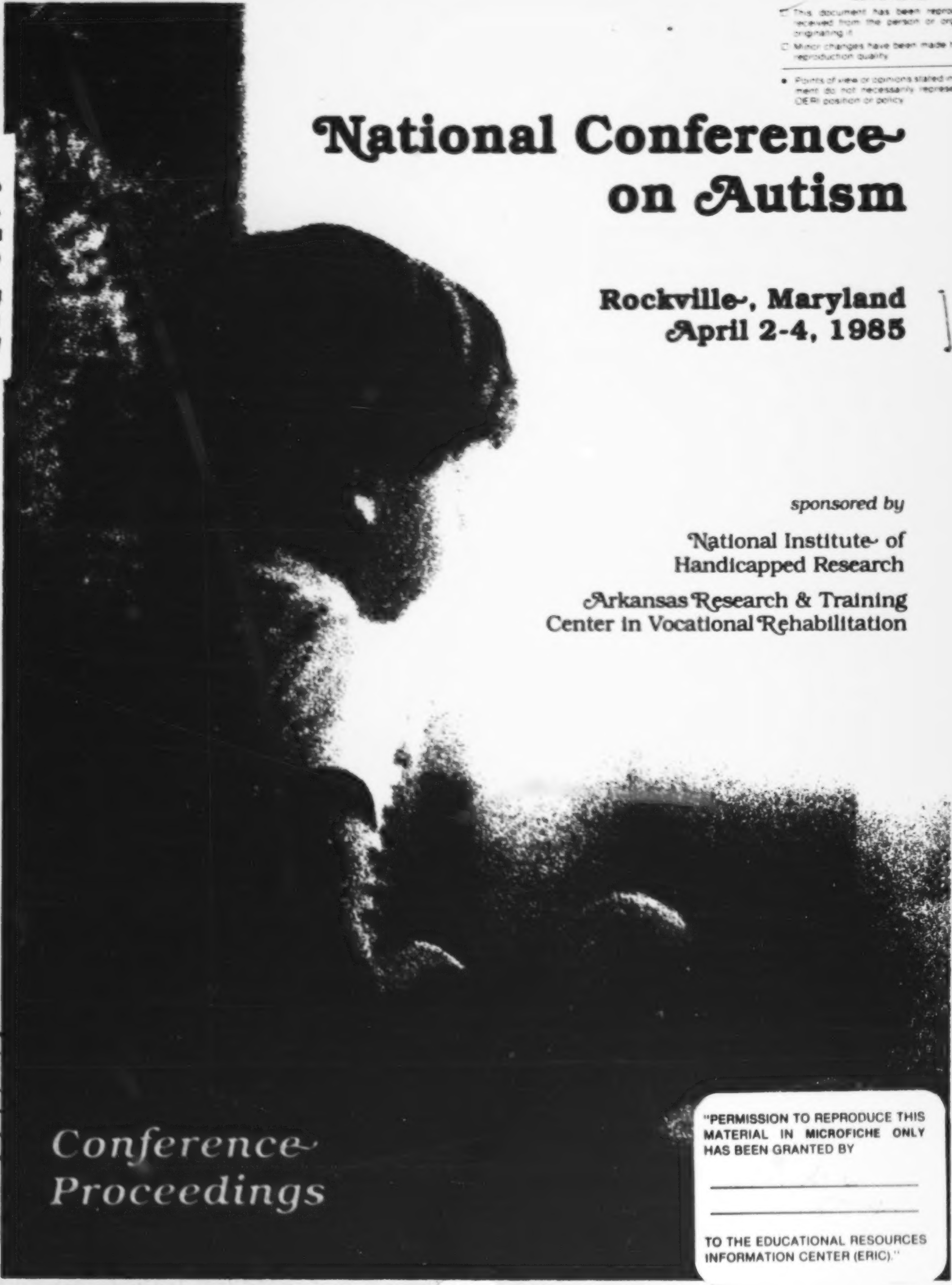
National Conference on Autism

Rockville, Maryland
April 2-4, 1985



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Conference Proceedings

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National Conference On Autism

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Introduction To The Conference Proceedings: Autism

B. Douglas Rice

Arkansas Research and Training Center
in Vocational Rehabilitation

Introduction

B. Douglas Rice

The National Conference on Autism held in Rockville, Maryland, was the realization of a long-time dream of many agencies, organizations, advocates and parents of children and adults with autism. For many years, these organizations and individuals had voiced the need for such a program in which leaders from across the country could come together to discuss common issues and concerns regarding the improvement and expansion of services for persons with autism.

Prior to this National Conference, representatives from various organizations concerned with autism (Rehabilitation Services Administration (RSA), Council of State Administrators in Vocational Rehabilitation (CSAVR), and the National Institute on Handicapped Research (NIHR) conducted several planning sessions in reference to this program, content, presenters, participants, and location. The final tasks for this National Conference were completed at a meeting of this committee in Washington, D.C., in December, 1984.

The success of this National Conference on Autism, hopefully, will lead to other even greater successes in the very near future. The fact that a large number of representatives from numerous agencies, organizations and advocates met together for a common purpose provides for optimism that, through a coordinated effort, there will be an increase in resources and funding which will expand services needed by persons with autism.

The conference itself followed a logical sequence exploring the scope of the problem, existing and available services, a description of the support system, observation of an effective program, and an outline of basic programmatic needs to improve service to this population.

Autism as a clinical entity was thoroughly reviewed including various theories as to etiology, treatment modalities, and widely held misconceptions. Conference participants were provided with an abbreviated but intensive symposium in the area of autism in order to understand the scope of the problem and the necessity for rehabilitation interventions that will provide for the integration of persons with autism into the mainstream of employment.

In addition to the vocational stategies, the necessary adult service systems to support vocational adjustment were presented with emphasis on full participation in society as the ultimate outcome.

The site visit to CSAAC and presentation on the staff development and training need of professional and support personnel were additional highlights of the successful conference. Further, an overview of a current and effective training program provided the participants with information that could be used to implement similar programs.

A key element inhibiting the provisions of meaningful services is the existing legislation and administrative practices of many agencies. A discussion of this legislation indicated that full pursuit of client rights might modify current practices and enable persons with autism to receive expanded services through rehabilitation programs. With the expectation that rehabilitation agencies would play a major role in providing services to persons with autism in the future, the state/federal rehabilitation program was presented to participants. Since the conference was designed to improve the understanding by professionals, service providers, parents, and advocates, the rehabilitation program was described in the terms of the current eligibility determination process, service delivery components, and limitation inherent in the system. Attention was also given to the many misunderstandings held by too many people in terms of the practices and potential of rehabilitation agencies.

Presently a new and innovative process that would modify state rehabilitation programs and enable persons with autism to access services was described. The Community Services for Autistic Adults and Children (CSAAC) in Rockville, Maryland, demonstrated to participants the effective use of a supported work model in various locations throughout the community where individuals with autism were working. The Conference participants endorsed the Supported Employment Model as the preferred strategy for serving this population.

Following these presentations, four small groups with specified assignments were organized to review current barriers to services and to make specific recommendations for action to reduce these barriers. These recommendations are included in this report.

Finally, participants were provided with the opportunity to listen to a brief summary of the conference and to look at **The Future of Services to Individuals with Autism** from Dr. Douglas Fenderson, former Director of the National Institute on Handicapped Research.

The proceedings that follow address many of the issues and concerns of agencies, organizations and special programs as well as advocates of services for autistic persons. A number of the presentations review the basic concerns and provide a basis for understanding and study of the more complex issues. Many of the more complicated problems are identified and addressed in the small-group reports and recommendations. These and other issues are already being brought to the attention of leaders in the human services field at the local, state and national level.

With information and advocacy comes awareness on the part of those in positions to impact on legislation and policies. True, wheels of progress move slowly, but they can be accelerated with additional support. This conference and these proceedings hopefully will increase the attention, services, and the resources needed by autistic individuals to assume their rightful roles as contributing and responsible citizens.

Agenda

National Conference on Autism

Sheraton - Potomac
I-270 and Shady Grove Road
Rockville, Maryland

April 2-4, 1985

Tuesday
April 2, 1985

12:30 pm - 1:15 pm	Conference Registration Orientation and Welcome	**Ms. Naomi Karp** Program Specialist National Institute of Handicapped Research **B. Douglas Rice, Ed.D.** Senior Training Specialist Arkansas Research and Training Center in Vocational Rehabilitation
1:30 pm - 2:00 pm	Welcome and Introductory Remarks	**Alton Hodges, Ph.D.** Acting Deputy Director National Institute of Handicapped Research
2:00 pm - 3:00 pm	An Overview of Autism	**Anne Donnellan, Ph.D.** Assistant Professor Department of Studies in Behavior Research Wisconsin Center for Education Research Madison, Wisconson **Martha Denckla, M.D.** Research Section Autism and Behavioral Institute of Neurological and Communicative Disorders and Strokes Bethesda, Maryland
3:00 pm - 3:30 pm	Break	
3:30 pm - 4:30 pm	The Vocational Rehabilitation System	**Peter Griswold** Director Michigan Rehabilitation Services Lansing, Michigan
4:30 pm - 4:45 pm	Brief Announcements	**Ms. Naomi Karp** **B. Douglas Rice, Ed.D.**
4:45 pm - 7:00 pm	Dinner (on your own)	

7:00 pm - 8:00 pm	Critical Dimensions of Non-Sheltered Employment Models	**Ms. Particia D. Juhrs** Executive Director CSAAC Rockville, Maryland **Marcia Smith, Ph.D.** Staff Psychologist CSAAC Rockville, Maryland
8:00 pm - 9:00 pm	Adult Service Systems	**Ms. Barbara Culter** Arlington, Massachusetts **Ms. Gerri Chestor** Lake Wood, Colorado **Robert York, Ph.D.** Community Integration Program Division of Community Services Madison, Wisconsin **Gary Lavigna, Ph.D.** Director of Behavior Therapy and Family Counseling Center Van Nuys, California
9:00 pm - 9:15 pm.	Announcements regarding CSAAC visit	**Ms. Patricia D. Juhrs**

Wednesday
April 3, 1985

9:00 am - 12:00 pm	Site visit to Community Services for Autistic Adults and Children Rockville, Maryland	**Ms. Particia D. Juhrs** Executive Director CSAAC **Frank Warren** Associate Director CSAAC Staff **Marcia Smith, Ph.D.** Staff Psychologist CSAAC **Ms. Susan Naylor** Vocational Program Director CSAAC
12:00 pm - 1:00 pm	Luncheon Meeting (Buffet)	**Ms. Patricia D. Juhrs** **Frank Warren** **Marcia Smith, Ph.D.** **Ms. Susan Naylor**
1:00 pm - 2:00 pm	Discussion of CSAAC Site Visit	**Ms. Patricia D. Juhrs and Staff**

2:00 pm **- 3:00 pm**	Staff Development and Training	**Jan Nisbet, Ph.D.** Assistant Professor Division of Special Education and Rehabilitation Syracuse University Syracuse, New York **Gary Mesibov, Ph.D.** TEACCH University of North Carolina Medical School Chapel Hill, North Carolina **Gary Lavigna, Ph.D.** Director of Behavior Therapy and Family Counseling Center Van Nuys, California
3:00 pm **- 3:30 pm**	Break	
3:30 pm **- 4:30 pm**	Legislation, Regulations and Economic Realities	**Ms. Marjorie DeBlaay** Annadale, Virginia **Frank Laski** Public Interest Law Center Philadelphia, Pennsylvania
4:30 pm **- 7:00 pm**	Dinner (on your own)	

Welcome and Introductory Remarks

Alton Hodges, Ph.D.
Acting Deputy Director
National Institute of Handicapped Research

Welcome and Introductory Remarks

Alton Hodges

It is a pleasure to be here, on behalf of Assistant Secretary Madeleine Will, to talk with the National Society for Children and Adults with Autism (NSAC), and with parents and professionals, about current program initiatives in the Office of Special Education and Rehabilitative Services (OSERS). I want to share with you the OSERS' view of the challenge to provide increased education and employment opportunities for developmentally disabled children, youth, and adults.

Our goal of ensuring that all disabled individuals have a chance to live independent and satisfying lives will be impossible to achieve, unless education is provided to every handicapped student in the least restrictive environment (LRE). This concept is becoming the cornerstone upon which federal special education policy is built. It certainly is the core around which our practices with regard to special education have evolved, in terms of early childhood and school-age programming and transition and adult services.

Indeed, the integration of disabled students with their non-disabled peers is the fundamental issue confronting parents and professionals who work with handicapped individuals to help them achieve maximum involvement in the educational, vocational and social fabric of American life.

Nearly three decades ago, chief justice Earl Warren wrote for a unanimous supreme court, "Separate educational facilities are inherently unequal. This inherent inequality stems from the stigma created by purposeful segregation, which generates a feeling of inferiority that may affect their hearts and minds in a way unlikely ever to be undone."

P.L. 94-142 establishes two of the basic principles concerning educational placement of handicapped children, which have come to be known as the "least restrictive environment" principles. First, there is a presumption in favor of placement in the regular educational environment—the regular classroom or the regular school setting. "Removal of handicapped children from the regular education environment" must only occur if and when "the nature and severity of the handicap is such that education in regular classes, with the use of supplementary aids and services, cannot be achieved satisfactorily." Thus, the first principle requires an educationally compelling justification for any proposed "separate schooling" of handicapped children.

The second, and broader, principle embraced within the statutory concept of "LRE" adresses the degree of student-to-student contact and integration, rather than the specific type of classroom setting. "To the maximum extent appropriate," provides the statute, "handicapped children, including children in public or private institutions or other care facilities," must be "educated with children who are not handicapped." Separation or segregation is permissible only when education itself cannot be successful without it, and even then, that separation or segregation must be limited by a concept of maximum appropriate integration. Both of these P. L. 94-142 statutory provisions require that state educational agencies adopt procedures to assure their implementation at the local level.

To these two statutory principles, regulations implementing the department of education's P. L. 94-142 added a third: education must be provided as close as possible to a child's home and, unless educationally compelling reasons exist, in the school which the child would attend if not handicapped.

As many of you know, the U.S. Court of Appeals for the 6th District has provided additional guidance by its question in a case involving the responsibility in an Ohio school district. It is important to note that the five most frequent justifications for more restrictive placement are not acceptable under this decision, the **Roncker** case.[1]

To summarize quickly, the five most frequent justifications for denying education in the least restrictive environment that we hear again and again are:

1. That related services are more easily provided in the separate setting.
2. That special equipment is available in a separate facility or there is a specially designed separate facility.
3. Better qualified teachers and professional and support staff are available in a separate facility.
4. That a particular program or curriculum is only offered in a separate facility, and,
5. That more intensive services are available in a separate facility because of the smaller teacher-pupil ratio.

The point of the **Roncker** decision, which established a kind of portability standard, is that all of these reasons are administrative in nature. Some of them are classroom specific, school specific, but certainly not school district or state-wide or national specific. These administrative impediments can be changed and modified. In the **Roncker** decision, at least, the court put the burden on the school system to make a pro-active effort to bring about these changes, and to explain why the particular ingredients of a program were not available in the least restrictive environment. I think this is a very important point at which we continue to hammer away.

We talk with so many parents in our work, and again and again we see them confusing least restrictive environment as the option, on the one hand, with no choice, on the other hand. By that I mean that so often parents come and define a program that they are familiar with as education in the least restrictive environment, and it is no program. It is not good LRE, it is not good special education. Therefore, they say, "I do not endorse the concept of least restrictive environment." In fact, what they are not endorsing is poor implementation of the least restrictive concept and poor implementation of the individualized education plan (IEP).

Another concern that comes from our conversation with parents and professionals is what we believe to be an insufficient understanding of the link between independent living, employment options for disabled adults, the absence of strong adult services, and LRE. All the chickens come home to roost when parents come and talk about the apathy, and in some cases, the hostility in their district toward the notion of creating adult services programs. Why this climate of lack of understanding? At least in part, it is the fact that planners and policy makers are not aware of handicapped children growing up to be adults and requiring a whole new set of services. We are breaking down this barrier now with our transition initiative, and we feel confident of its success.

But there is an important link between the desire on the part of parents for the most independent, most productive life for their handicapped child, and the preparation and teaching of skills required for that child, and the preparation and teaching of skills required for that child to function in the adult environment.

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[1] **Roncker** v. **Walter** 70 F. 2d 1058 (1983). In the **Roncker** case, the court, referring to the "very strong congressional preference" for mainstreaming reflected in P. L. 94-142.

A related concern expressed by parents and professionals involves situations in which there's a mad rush at the end of high school to teach socialization skills to adolescents. In an instance, professionals tried work-study programs and found that the skills for doing the job were present, but that the child was doing very poorly in dealing with supervisors and co-workers. He had not learned appropriate socialization skills.

With the help of professionals who act as job coaches and personal advocates, many handicapped individuals, including those with developmental disabilities, are learning necessary socialization skills while engaging in meaningful employment in supported work programs.

Assisting in the implementation of supported employment programs at the state and local level is one of OSERS' biggest current priorities.

We have received support in the President's fiscal year 1985 budget for an initiative to provide employment opportunities and related services to individuals whose physical or mental disabiliites are so severe that they do not qualify for traditional vocational rehabilitation services.

This initiative assists states in their implementation of supported employment programs as an alternative to the day activity services that now include many individuals with severe disabilities.

As we envision it, supported employment combines the ongoing support typically provided in day activity programs with paid work opportunities.

Such "supported employment" programs could occur in a variety of settings:

- In dispersed individual placements in a community, with publicly-funded support staff rotating among sites; or
- In a mobile crew working in neighborhood settings; or
- In group placements, with many individuals hired as a team, supervised directly by a job coach.

Supported employment is defined by four characteristics that together distinguish it from both vocational rehabilitation services and traditional methods of providing day activity services:

1. **Service Recipients** - Supported employment is designed for individuals who are serviced in day activity programs because they appear to lack the potential for unassisted competitive employment and consequently are not served by the vocational rehabilitation system.
2. **Ongoing Support** - Supported employment involves the continuing provision of training, supervision, and support services that would be available in a traditional day activity program. Unlike vocational rehabilitation programs, supported employment is not designed to lead to unassisted competitive work.
3. **Employment Focus** - Supported employment is designed to produce for disabled persons the same benefits from work that other people receive. Employment quality can be measured by: income level, quality of working life, security, mobility, advancement opportunity, etc. In contrast, outcome measures currently used in day activity programs reflect mastery of skills and behaviors that are thought to be prerequisite to obtaining employment and receiving employment benefits.

4. **Flexibility in Support Strategies** - Supported employment incorporates a variety of techniques to assist individuals in obtaining and performing work. For example, support could involve assistance to a service agency that provided training and supervision at an individual's worksite; support to an employer to offset the excess costs of equipping, training, and supervising a severely disabled individual; and salary supplements to a co-worker who provided regular assistance in performance of personal care activities while at work.

The central part of the OSERS supported work demonstration is a one-time, time-limited, grant, contract, or cooperative agreement program that provides funds to help states convert traditional day activity programs to alternative supported employment methods.

In order for supported employment programs to be effective, we need people who are trained to develop jobs, match individual strengths to work tasks, communicate with employers, plan transportation, and handle complex interactions with social security, education, and related programs.

Job coaches or trainer advocates will be needed to work closely with difficult to place workers until they learn to function at an acceptable performance rate (i.e., in bench work, electronic assembly, or other entry-level positions).

As needed, job coaches should perform the work themselves to assure employers that the job will be done correctly, and to act as role models for the employees.

New personnel will also learn what is involved in monitoring the employee's progress on the job, getting regular written feedback from employers and co-workers, utilizing behavioral data, and implementing communication with the employees' families. They will learn what is involved in helping an employee keep a job.

Social skills also play a major role in an individual's ability to succeed in the workforce. These job coaches play a pivotal role in the development and enhancement of social skills which may be lacking in some severely disabled individuals at the time of their entry into supported employment programs.

Intensive, individualized and ongoing training tends to be expensive. But we contend that supported employment programs are less expensive in the long run than total public support. This is, however, a one-time cost, after which most trainees become at least partially self-supporting.

Developing of viable supported employment programs is slowly replacing institutionalization and day activity programs as the method of choice in dealing with severely handicapped individuals. Indicative of this trend is the vocational program at community services for autistic adults and children, in Rockville, Maryland. Other states and localities have demonstrated great interest in replicating this excellent program, in which two dozen adults with autism work in a variety of small manufacturing firms. The jobs held by these adults include the assembly of machine parts; the cutting and shaping of copper tubing; welding; and the binding of printed books and pamphlets; and the recycling of industrial materials.

Tomorrow, our visit to the Rockville program, and to the other impressive supported employment facilities in suburban Maryland, will provide first-hand evidence of ways supported employment can enrich the lives of severely handicapped individuals.

At this time, supported employment programs for severely handicapped youth and adults make up only a tiny fraction of the programs available. But they provide a powerful demonstration that, with assistance, even individuals with the most severe physical and mental handicaps can move from welfare programs to employment programs.

We, as professionals and parents, can facilitate this process by our vigilance in requiring that states and local jurisdictions provide adequate educational and employment services for their disabled citizens. This will ensure that all disabled individuals, regardless of the severity of their handicaps, are afforded the opportunity to achieve their maximum potential as independent, self-sustaining adults in the communities in which they live.

Thank you.

An Overview of The Rehabilitation Of Persons With Autism

Anne M. Donnellan, Ph.D.
Assistant Professor
Department of Studies in Behavioral Research
Wisconsin Center for Education Research
Madison, Wisconsin

An Overview Of The Rehabilitation of Persons With Autism

Anne M. Donnellan, Ph.D.

Autism - Historical Overview

In 1943 Kanner first presented his impression of 11 children he had seen over the course of eight years whom he believed had not previously been described in the psychiatric literature. He noted their disturbances in affective development, language deficits and apparent need to maintain sameness in their environment. It is to the credit of this fine clinician that, on the basis of so few cases, he was able to detect the critical features of a syndrome which had escaped everyone else. Moreover, as noted by Rutter (1978) and others, Kanner's early work has more than historical value in that his descriptions are so fine that they can be read with profit today by any student of human behavior.

The many detours and conceptual diversions of writers and practitioners that were engendered by Kanner's early work, however, necessitate putting that work into an historical perspective. Without such a perspective, it would be almost impossible to begin to fathom the breath, variety and controversial nature of essentially every aspect of this relatively rare but fascinating syndrome or to understand the absence of useful information in some basic and critical areas.

In 1943 Kanner was writing to a relatively new field and one which was being impacted by European emigres, many psychoanalytically trained. To this audience, he wrote, "We must, then, assume that these children have come into the world with an innate inability to form the usual, biologically provided affective contact with people..." (p. 249). Despite this caveat, Kanner's readers, particularly in North America, picked up on his descriptions of the parents of these children as "highly intelligent," "obsessive," "mechanical" and "cold." Coupled with the apparently normal physiognomy, the rigidity and the autistic "aloneness" of the children and Kanner's own later equivocation (Rutter, 1982 b), many erroneously assumed autism to be a withdrawal reaction to poor parenting. Through the 1950s and into the 1960s, approaches expounding the theories of schizophrenogenesis and promoting psychoanalysis for these children had a dampening effect on research into more parsimonious explanations and more effective treatment, (see Donnellan, 1985, for a review).

By the early 1960s, however, researchers were demonstrating the effectiveness of behavioral techniques. Against this backdrop of ineffective technology and fuzzy explanatory systems, empirically verifiable and replicable results had a dramatic effect. It is not unfair to say the pendulum swung to the other extreme. That is, a field which was early dominated by theoretical constructs and devoid of empiricism or technology was subsequently dominated by technology with little concern for unifying content or concepts. Although the contribution of that technology is enormous, it has often resembled Bronfenbrenner's (1977) characterization: "...the science of the strange behavior of children in strange situations with strange adults in the briefest period of time."

Much of the recent literature in autism has begun to incorporate relevant content from a wide variety of disciplines within the framework of effective technology. It is that changing literature which will be highlighted in this presentation. Major topics to be covered are: characteristics; communication; social interaction/integration; assessment; behavior modification; curriculum; and adolescents and adults.

Summary Content

Characteristics

General

Several fine references are available which describe the complex interaction of linguistic, social interactional and behavioral characteristics of autism. Of the early works, Rimland's (1964) text is still extremely useful as is Wing's (1976) book for parents and teachers. Ruter and Schopler's (1978) volume is a comprehensive review of some of the best research in the field from both sides of the Atlantic. Cohen and Caparulo (1975), Rutter (1982) and Wing (1981) provide good brief overviews and DeMeyer, Hingten, and Jackson (1981) present an exhaustive summary of the research of the past decade. As noted earlier, Kanner's (1943) descriptions of the characteristics of autism are still important, and all the more interesting in light of recently acquired knowledge. Cohen and Donnellan (in press) is an authoritative collection of recent research and successful interventions in medicine, biochemistry, neurology, psychology, linguistics, education, vocational residential and legal issues pertaining to persons with autism. Ornitz and Ritvo (1977) include an overview of some biological research, Ritvo and Freeman (1978) review the critical features of the disorder as they are defined in the working definition of the National Society for Children and Adults with Autism (NSAC); and Siverts, Jensen, Martinsen, and Sundert (1982) review sixty different uses of the diagnostic category of autism. Finally, Lovaas (1979) and Koegel, Egel, and Dunlap (1982) provide an overview of the contribution of behavioral psychology to understanding and teaching individuals with autism.

Cognition

Cognitive development issues in autism are extremely complex (see Rutter, 1982b, in the Characteristics section). Early writers assumed that all individuals with autism had normal or better intelligence and that any measurable retardation was a function of social withdrawal or lack of motivation. More recent evidence indicates that, independent of social/motivational issues, most persons with autism are functioning in the retarded range (Rutter, 1978). However, as indicated by many of the writers included in this presentation, autism cannot merely be seen as a form of retardation. Many persons with autism, perhaps as many as one-third, fall at least within the normal range of intellectual functioning. Yet, these "near normal" persons often are severely impaired socially and linguistically and many need services typically required by more severely retarded persons (AABT Report, 1980; see Kilman & Negri-Shoultz, in the Adolescents/Adults section, in press, for a review of the literature on persons with autism and near normal intelligence). Across the cognitive range, persons with autism display distinctive patterns of ability, typically with strengths in visual spatial abilities and deficits in areas of linguistic functioning. The experimental work by Hermelin (1982), Hermelin and O'Conner (1964), and Hermelin and Firth (1971) (see Characteristics section) are particularly helpful for persons wishing to comprehend the complex nature of the cognitive disability in autism and in particular its relationship to social interaction.

Communication

It is not surprising that this group of documents represents the largest category of citations. Problems in language comprehension and usage, as well as social interaction for persons with autism have been viewed as cardinal features of the syndrome throughout its 40-year history (Kanner, 1943; Rutter, 1982, both in the Characteristics section). It is also one of the categories that best exemplifies the changing character of the literature.

Echolalia

Echolalia, or echoed speech, is a good case in point. Kanner's early work (1943; 1946) noted that the echoes often served specific functions for individual children such as affirmation by repetition. Later writers sought to understand the underlying causes of the psychosis through an analysis of the symbolism in the echoed speech. Many technologists, on the other hand, suggested that echolalia interfered with normal speech development and recommended that it be eliminated. However, recent data indicate that, indeed, echolalia can serve communicative functions (Prizant & Duchan, 1981; Prizant & Rydel, 1984). These functions, through idiosyncratic, are not necessarily irrelevant or dispensable. The references chosen for this presentation reflect the shift from those ideas which represent a fairly rigid notion of speech and language development to those which attempt to incorporate concepts and procedures from a variety of disciplines.

Training Issues

As noted earlier, by the 1960s operant techniques were clearly shown to be beneficial in developing speech in children with autism irrespective of underlying cause. Several articles describing these techniques are included, as is the 1977 Lovaas book on language acquisition through behavior modification. Several writers note that this technology has much to offer to increase the linguistic competence of the autistic population but it may be hampered by its own structural approach (e.g., Schuler, 1980, see Communication-General section) or by the linguistic deficits of the individuals (e.g., Howlin, 1981). Whatever the reason, the goal of developing effective and reliable methods for training generalized or spontaneous language in individuals with autism has met with limited success (Fay & Schuler, 1980). As noted below, with an expanded understanding of the issues, there is reason to be optimistic about our ability to give these individuals greater communicative competence.

Pragmatics

The failure of previous attempts to develop language fluency with operant techniques may be the result of a failure to attend sufficiently to context. It has been suggested that our understanding of behavioral psychology needs to expand to incorporate information from other disciplines such as linguistics (e.g., Carr, in press). One area of inquiry in language and autism which, though relatively new, shows great promise is the study of pragmatic development in these individuals (Duchan, 1982). Pragmatics is an area of linguistics that looks at the functions of language in context and is related to what Duchan (in press) refers to as "sense-making." Certainly, it is an area which will continue to interest researchers in autism because conventional "sense-making" is extremely difficult for persons as literal minded as autistic indidividuals. The ability to "sense make" is embedded in culture and context. Thus, a sentence such as "The man was hungry so he picked up the yellow pages" would be almost incomprehensible to any person with autism, even one who is intellectually "normal." Along with social interaction development, the development of pragmatic functions of language is an area of research in which persons with autism offer what Shapiro (1977) refers to as "the ultimate experiment." (See Communication—General Section.) Several of the citations on social interaction describe the deficits (e.g., Wing & Gould, 1979, see Social interaction/integration section) as well as suggested strategies for remediation (e.g., Kilman, 1981; Kilman & Negri-Shoultz, in press, see Adolescents/Adults section).

Augmentative and Alternative Systems of Communication

Despite the many positive results of attempts to teach speech to persons with autism, (see Training Issues section) it appears that some 50% of this population are likely to remain functionally mute (Rutter, 1982; see Characteristics section). This fact, combined with the noted interest in the pragmatic aspects of language, has spurred interest in the development of non-speech systems of communication. The most common system is signing (and 12 articles are included on the topic). It has been noted that signing also has limitations for this population both because of its temporal properties (Schuler & Baldwin, 1981) and because of its limited usefulness in complex, heterogeneous community settings. Several authors suggest that the emphasis should be less on language development and more on communication (e.g., Schuler, 1980) and offer a variety of augmentative systems (Voder & Calculator, 1981) such as the written word, pictorial systems and computer technology. Prizant (1982) presents a comprehensive view of what speech and language clinicians can do to assist persons with autism to develop more conventional and appropriate systems for communicating in a variety of environments.

Social Interaction/Integration

Many of the more recent articles about autism have begun to stress the social interaction difficulties as central to the disorder. Obviously, these are highly correlated with the language, cognitive and communicative characteristics of this population (Hermelin, 1982; Prior, 1984). Included in this section are articles that discuss the needs of persons with autism in the area of social skill development and some that have been successful in mediating such deficits (e.g., Donnellan & Kilman, in press). Also included are articles that present strategies for maximizing the opportunities for persons with autism to improve their social interaction skills through integration with non-autistic, non-disabled peers and others (e.g., Mesaros, 1984; McHale & Simeonsson, 1980; Strain, 1984).

Assessment

Testing

Seven articles are included on assessment of individuals with autism, attesting to the complexity of the syndrome. Most of the papers concerned with standardized testing stress the need to choose instruments and testing strategies which take into account the behavioral, linguistic and cognitive characteristics of this population. That is, they exhort the testor to pay particular attention to the language content of the tasks as well as motivational and attentional variables. Some of the tests discussed are designed to either diagnose autism or are specifically designed to test abilities of autistic individuals. These tests can provide some useful information about learning strengths and strategies of the individual. However, caution must be used in attempting to build training sequences or curriculum based on any standardized assessment or behavioral checklist because assessment and curriculum development are separate though related processes. The fact that someone cannot do something is not an automatic indication that he/she needs to learn it. Brown et al. (1980) in the Curriculum section, suggest issues to address in setting priorities. Additionally, more recent articles on assessment suggest a greater interest in assessment of social, linguistic and adaptive behavior than in traditional assessment of overall intelligence, (e.g., Sailor & Horner, 1976; Schuler & Goetz, 1981).

Vocational Evaluation

There was little information available on vocational assessment or even vocational training for individuals with autism. As more school-aged post-Public Law 94-142 students reach adulthood, vocational issues are certain to attract more attention. The same cautions regarding standardized tests are likely to apply to vocational testing. Some writers (e.g., Brown, Nietupski, & Hamre-Nietupski, 1976; see Curriculum section) strongly suggest that vocational and other assessments be "low influence," that is, carried out in the context in which the skill must ultimately be performed. See Brown, et al. (1983) for a discussion and strategy for low inference vocational assessment. The few reports of the ability of persons with autism to perform meaningful work in non-sheltered environments certainly support the validity of this notion (Gorski, 1983, see Adolescents/Adults section). This is an area of much needed work in research and demonstration.

Behavior Modification

Persons with autism present a range of problem behaviors which have been handled in a wide variety of ways. The characteristics of autism previously mentioned are helpful in understanding recent changes in notions about the management of behavior problems with this population. First, it is recognized that the communicative/social interaction deficits of autism are such that these may help to explain the apparent "non-compliance" (e.g., Volkmar & Cohen, 1982); tantrums, outbursts or even severely injurious behaviors (Carr, 1977; Iwata, Dorsey, Slifer, Bauman, & Richman, 1982). Thus several recent authors are concerned that practitioners consider the communicative function of aberrant behavior before they attempt to eliminate it. There is some indication that when a person is given an alternative system, behavior reduction strategies often may be unnecessary (see Donnellan, Mirenda, Mesaros, & Fassbender, 1984, for a review of this issue).

Second, the social interaction deficits of autism may be the real issue; often the problem is not the behavior but the manner or the situation in which it is performed. Rather than eliminating it, there is a need to bring the behavior under more appropriate stimulus control (e.g., Donnellan & laVigna, in press). Again, positive programming which attempts to teach persons with autism to "sense make" (Duchan, in press) in complex social environments is the real key and several recent papers address this area.

Finally, even where there is a need to reduce or eliminate a behavior, it is clear that administrative, legal, and ethical concerns will preclude many of the aversive options which have been utilized in the past (LaVigna & Donnellan, 1985; Martin, 1975). Many of the more recent articles on management offer examples of effectively dealing with the behavior problems associated with autism using non-aversive interventions (e.g., Smith & Coleman, in press).

Curriculum

In contrast to the behavior modification issues, the category of curriculum for students with autism had one of the shortest bibliographies. This may be due to the excessive reliance on technology suggested earlier. The few available articles, almost without exception, are based on a "readiness" model, which assumes that most persons with autism will eventually be appropriately served via a regular education curriculum. Other articles outline curriculum strategies that are highly dependent upon developmental checklists with little regard for chronological age appropriateness or the functional relevance of the task for the individual (see Mirenda & Donnellan, in press, for a review of this issue). Given the learning, language and social problems of autism, recent writers have been concerned that curriculum development strategies ought to relate more directly to the ability of adults with autism to function as productively and independently as possible in a variety of heterogeneous community-based environments (Brown et al., 1976; Donnellan, 1980; Donnellan & Neel, in press). Much of the important curriculum work in this area of natural environment teaching comes from professionals concerned with severely retarded individuals. Thus, several articles are also included that are concerned with curriculum development strategies for other severely disabled learners.

There are a number of citations included in this section that address techniques demonstrated to be useful for teaching persons with autism. Among those included are articles on discrete trial format (Koegel, Rincover, & Russo, 1977; Woods, in press, see

Behavior Modification section); incidental teaching (Carr, in press, see Communication/Training Issues section); time delay (Snell & Gast, 1981); cues and correction procedures (Falvey et al., 1983); whole task teaching (Gold, 1982); as well as some articles which suggest ways in which various technologies might be adapted to be more useful in natural, non-sheltered environments (Donnellan, Mesaros, & Anderson, 1984).

Observations and Recommendations

It is clear that no brief review can fully address the many complex and fascinating aspects of understanding and effectively interacting with individuals with autism. Observations and recommendations will be limited to those issues particularly related to serving adults.

Observations

Though thousands of articles have been written about persons with autism, surprisingly few have direct relevance for rehabilitation counselors and others concerned with the education and rehabilitation of adults. In part this is due to the early notions of psychogenesis which provided little effective treatment and, consequently, few incidences of successful outcome in adulthood (Lotter 1978; see Adolescents/Adults section). The paucity of adults with autism in non-institutional settings created an information void regarding adult functioning. Moreover, as technology was developed and shown to be effective, little attention was paid to context or content. Thus, there are relatively few studies which demonstrate effective use of technology outside of schools or clinics or for teaching complex tasks performed in non-sheltered vocational and other community based environments. The information from many of the articles and texts referenced here will need to be extrapolated to adult functioning and heterogeneous settings. The following are recommendations for research and demonstration projects to provide this critically needed information in order to support and enhance the functioning of adults with autism in heterogeneous community settings.

Recommendations

Future research should address all of the categories and subcategories delineated in this presentation because the empirical information available is sparse relative to the need (see Donnellan, Mesaros and Anderson, 1984). At a minimum, the following areas deserve special attention:

1. **Life space options for adults with autism**

   Historically, most adults with autism have lived out their lives in extremely restrictive and non-habilitative environments (Lotter, 1978). Recent reports indicate that this need not be the case if alternative environments and interventions are utilized (Gorski, 1983; LaVigna, 1983; Hitzing, in press; Smith & Cleman, in press).

   - **a.** Demonstration projects are needed to delineate critical factors in developing life space options for persons with autism including staffing patterns, staff training, heterogeneous groupings, placement and support strategies.
   - **b.** Studies that generate longitudinal data and social validation data on life space options are critically needed.

c. Persons with autism frequently have skills which can be beneficial in many vocational settings. Studies and demonstration projects that attempt to match individuals to work settings and tasks, and delineate how such matches affect performance, longevity and behavior are essential.

2. Social Interaction and Communication

As indicated, the emphasis on functional communication, social interaction and pragmatics is a fairly recent trend in the autism literature, albeit one that shows promise. Much more research is needed, however, in this exceedingly complex area, (e.g., Hermelin 1982).

a. Basic research is needed on the complex interaction of linguistic, cognitive and social skill development in autism.

b. Research demonstration projects that delineate ways to utilize behavioral technology, develomental assessment and chronological, age-appropriate, functional tasks to enhance social skill development are essential for people with autism.

c. Applied research is necessary in non-sheltered environments utilizing augmentative communication systems to assist mute or nearly mute persons with autism to succeed in such settings.

d. Strain (1984), McHale (1983), Mesaros (1984) and others have demonstrated the potential value of heterogeneous placements for young children with autism. Much could be learned from studies that address the effect of such placements on the social development of adults with autism.

3. Non- Aversive and Non-Stigmatizing Technology

The emphasis on normalized and less restrictive options provides another rationale for non-aversive and non-stigmatizing techniques for dealing with persons with autism.

a. Research is needed to develop a broad range of non-punitive intervention strategies for directing aberrant behavior in natural environments.

b. Recent insights into the communicative functions of aberrant behaviors need to be researched and expanded upon.

c. The potential use of such procedures as differential reinforcement of low rates of behaviors and differential reinforcement of other behavior (see LaVigna & Donnellan, 1985, for a review) with the context of the natural breaktimes of vocational sites merits research attention.

d. Little is known about the applicability of covert conditioning and self-control procedures for this population and research into this area would be invaluable in managing problem behaviors of adults and in a variety of adult environments, (e.g., Groden, 1982; Mirenda, 1985, in Behavior Modification section).

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New Concepts of Autism And Related Disorders

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New Concepts of Autism And Related Disorders

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Definitions

According to Diagnostic and Statistical Manual of Mental Disorders 3(1980) "early infantile autism" is now classified among the pervasive developmental disorders. The disorders which also are grouped under pervasive developmental include "childhood onset pervasive developmental disorder" and "atypical pervasive developmental disorder," which differ from early infantile autism in that age of onset and extent of language deficit are less stringently specified (see the Checklist). Taken as a group these three syndromes, either in their full or "residual" form, constitute the group which the National Institute of Neurological and Communicative Disorders and Strokes is referring to by the term "autism and related behavioral disorders." The "atypical" category may be taken to include Asperger's Syndrome and "social-emotional learning disabilities."

Diagnostic criteria for infantile autism include onset before 30 months of age, pervasive lack of responsiveness to other people, gross defects in language development (which may be mutism, a complete lack of speech and language, or language which is markedly anomalous, with **peculiar** speech patterns such as immediate or delayed echolalia, pronominal reversal, and the repetition of snatches of language which are irrelevant to the context). Comprehension is usually impaired and pragmatic language defects are prominent, **i.e.**, the language does not contribute to or relate to the communications situation. Other criteria are more difficult to operationalize clinically. These include the **absence** of delusions, hallucinations, loosening of associations or schizophrenic-type incoherence and presence of bizarre responses to various aspects of the environment, **e.g.** resistance to change, interest in or attachment to certain objects, painfully augmented levels of response to sound or (less frequently) certain visual or kinesthetic events. The **essential** features are the early onset (within the first 30 months of life) the lack of responsiveness to other people and the gross impairment in communicative skills. Except for the third, these are not readily documented characteristics; thus, agreement upon membership in the diagnostic category is difficult to achieve.

The failure to develop interpersonal relationships is characterized by an apparent lack of interest or lack of responsiveness to people. In infancy these deficiencies may be manifested by a failure to cuddle, by lack of eye contact, by a pulling away from affection or physical contact or by a very primitive egocentric level of relating to (other people only in order to meet personal needs). Adults may be treated as totally interchangeable with no distinction being made between "family friends", relatives and total strangers; or in other instances the child may cling to a specific individual and resist all others, yet relate to that individual mainly as a means towards a fulfillment of basic needs.

In early childhood there is social constriction and maldevelopment of social skills, so indeed it appears that the most long-lasting aspects of the syndrome, even in those characterized as "high-functioning" intellectually, involve a difficulty in social interactions. This is so even when aloofness or lack of desire to relate is no longer apparent.

Impairments in communication include both verbal and nonverbal skills. Language may be totally absent, or when it develops it is often language that shows peculiar grammatical structure such as use of the pronoun "you" when "I" is the usual usage, inability to use anything but very concrete terms, highly idiosyncratic uses of words in ways which do not fit the common meaning for these terms, delayed or immediate echolalia and abnormalities of speech prosody. The latter abnormalties may be at either of the ends of the spectrum, either complete flatness and monotonous "robot-like" speech or extremely exaggerated "theatrical", peculiar vocal melodic contours. Nonverbal communication, in the form of accompanying facial expressions or hand gestures, is often impaired and imaginative play in the sense that pantomime is a form of communication among normal children is lacking in the full syndrome of autism.

The bizarre responses to the environment may take several forms, the most often emphasized one being resistance and even overwhelming "temper tantrum" reactions to minor changes in routine or in the spatial arrangement of the environment. There is often idiosyncratic attachment to particular odd inanimate objects such as tissues, bits of fluff which are shed from garments, strings or rubber bands. Some children show a fascination with watching, touching, or playing with mechanical devices such as whirling, vibrating or knocking radiators and other very regular, predictable mechanical devices. The child who is autistic may have an extremely narrow band of interest in certain objects, parts of the body, machines, or rote topics such as airplane or train schedules or historical dates. In rare cases, musical or artistic ability is not only spared but is a narrow band of interest and accomplishment that may go well beyond the ordinary level expected for chronological age. The NSAC definition of "autism" places more emphasis on sensory peculiarities and motoric repetiveness than does DSM III.

About 40% of autistic children have I.Q.'s measured below 50 and only 30% have an I.Q. of 70 or more. Where there are discrepancies, they are usually in favor of tasks requiring rote verbal proficiency or manipulative-visual-spatial skills. Rarely is performance selectively spared for tasks requiring reasoning, logic, symbolic or inferential thought. The special spared areas are usually on a perceptual-motor or rote level of accomplishment.

By definition, the age of onset should be before 30 months but of course clinically it may be difficult to be absolutely sure about establishing the age of onset if the child is being seen some time past the third birthday, since parents of children who are under clinical scrutiny often remember items which tend to confirm the present abnormal state. Some clinicians have been impressed by a subgroup which seems to be normal until around the second birthday and then with some stressful, traumatic, or perhaps even infectious event undergoes a dramatic regression. Another subgroup seems to have always been abnormal in responsivity and developmental deviancy has been prominent since birth.

Associated features may be hyperactivity, mood lability, temper tantrums, idiosyncratic giggling or laughing without identifiable environment stimulus, overresponsiveness or underresponsiveness to particular sensory stimuli such as sounds, light, or even bodily pain. There may be tremendous anxiety over environmental events which seem of no consequence to others and total lack of fear or appreciation of real dangers such as heights or vehicles. Some peculiar repetitive nervous habits, in some cases extending even to self-mutilation, may be present. Rocking or other rhythmic body movements are very frequently seen and repetitive movements may include twirling a piece of hair, repeatedly playing with the fingers in front of the eyes, and a vast repertoire of stereotypes. Recently, neurologically-oriented observations of children with autism have brought into the consciousness of child neurologists disturbances of motoric function including abnormalities of postural fixation and righting reflexes, involuntary movements, alterations of muscle tone in the direction of rigidity or hypotonia (but not spasticity, akinesia or diskinesia) sometimes combined, and the frequent occurrence of the "emotional" facial paralysis (also known as "reverse" facial paralysis, since its manifestations are the opposite of those of the more familiarly taught lower facial paralysis associated with lesions of the corticobulbar system.) Some of these recently highlighted striking clinical abnormalities of motility are more easily discerned in the older child, adolescent or adults. An as-yet-unresearched possiblity is that there may actually be a gradual emergence of motility pattern disturbances with increasing age (the alternate explanation, of course, being that it is so very difficult to perform anything like a formal examination on younger children with this pervasive developmental disorder.)

Seizures occur post-puberty in 20-40% of children diagnosed as "autisic." As yet, the EEG and clinical characterization of seizures has not been pursued in detail.

The course of the infantile autism disorder is chronic and the prognosis rather poor for all but about 3 to 5% of the most high functioning children. Special educational facilities are always necessary at least until early adult life when, if there is a special skill, even in a narrow band, compatible with some degree of independent living skills and social skils, sheltered workshops and institutional settings are the rule rather than the exception as adult-life outcomes. Factors related to long-term prognosis include I.Q. and the development of functional language skills. One child in six with this diagnosis makes an "adequate" social adjustment and is able to do some kind of regular work by adulthood. It cannot be overemphasized that the social awkwardness persists even after other aspects of the disorder have been remediated, and many young adults develop reactive depression when their emerging interest in people is not matched by their social skills.

Closely related to the clinical description in DSM III of "residual" autism is Asperger's Syndrome, which consists of impairments of development of social interractions without the severe language characteristics of the classical autistic syndrome (although conversational skills are anomalous). The description, following as it did very shortly after Kanner's original description of infantile autism, is remarkably similiar conceptually and also goes by the name "Van Krevelen's autistic psychopathy". Children with Asperger's Syndrome begin to speak at the age expected in normal children, but the content of their speech is abnormally pedantic and often consists of long discourses on favorite personal subjects. Nonverbal aspects of communication are abnormal with little facial expression except with very strong emotions; vocal intonation tends either to be very flatly monotonous and droning or else peculiarly overly exaggerated, gestures are limited or else again inappropriately fixed at a level which is embarrassingly theatrical; and perception (or comprehension) of other people's vocal and facial affective expressions or gestures is extremely poor. The person with Asperger's Syndrome may misinterpret or completely ignore nonverbal signs, at times earnestly gazing into another person's face searching for the affective message which eludes him. The obvious characteristic and that which conceptually links it with classical or Kannerian autism is the "core" impairment of bidirectional social interraction. Apparently there is a fundamental problem with social cognition in these children so that they have a disability in perceiving, understanding and using the rules governing ordinary social behavior. They do not seem aloof or undesirious of social interractions. Severe psychiatric illness is common in adults with Asperger's syndrome.

I have been struck by the resemblance between what is described as Asperger's syndrome and what has been observed by myself and others (Roourke 1982) among children and adolescents with Right hemisphere dysfunction. They have a constellation of signs of social imperceptions and/or output dysfunction with other neuropsychological signs of impaired visual-spatial processing. This does not mean however that the only locus which is a "candidate" for lesions underlying Asperger's syndrome is Right cortical; in fact, subcortical systems preferentially involved in some of the nonverbal perceptual-motor mechanisms underlying social behavior may be linked to Right cortex more so than to left. In developmental disabilities, a brain-to-brain ontogenetic relationship of "localization" must never be an ignored possibility. In other words, the Right coritcal systems may be dependent upon the integrity of more primitive or basic subcortical systems feeding information into them in order for the performance of socially-relevant perceptions and actions to develop in the child.

Looking over the behavioral signs of autism and related disorders, meaning basically that one sets aside the severe communications handicap that overlaps with the developmental dysphasias, one sees that the signs of autism include flattened affect, profoundly impaired interpersonal relationships, failure to react in the well-modulated normal range to sensory experience both pleasurable and painful, resistance to change, rigid and stereotyped repetitive behaviors and in some children self-mutilation such as biting or headbanging. Such signs might suggest a severe disorder in the limbic system, the mesial limbic system and its bordering zones in thalamus and basal ganglia having been suggested by Damasio and Maurer (1978). There are possible biogenic amine disorders, endogenous opiate or amphetamine receptor dysfunctions with any one of the above. Testable autistic children typically have lower verbal and performance IQ scores, but Rutter has indicated that the IQ remains a good prognostic indicator of outcome even if its meaning is open to debate. The fragmentary evidence collected thus far does not provide the basis for a unitary hypothesis concerning the cause of autism. In fact, autism is probably a final common expression of multiple determinants having something to do with related anatomical and biochemical systems and underlying mechanisms may be obscured by the diversity of causations. Thus far it has appeared quite clear that disorders of the autistic spectrum can result from several diseases of specific etiology; neurofibromatosis, tuberous sclerosis, hydrocephalus, infantile spasms (hypsarrhythmia), phenylketonuria, congenital deafness or blindness, specific congenital rubella syndromes and a variety of specific brain insults, particularly viral encephalitis with a predilection for the limbic system, have been reported to produce autistic behavior. Those cases in which there has been normal development and then a specific age at which regression is noted have suggested to many investigators an undiagnosed slow or smoldering viral infection of the nervous system of the type that can run its course and leave the child with devastating deficits.

Autism at the present time is viewed as rarely, if ever, a psychogenic or environmentally-responsive reaction pattern. On the other hand, environmental factors can mitigate, ameliorate, or aggravate the symptom complex.

Even the oldest and best replicated biological finding of hyperserotonemia within the biomedical hypothoses about autism remains in need of further studies. We need to know how the brain function or behavior relates to peripheral blood serotonin measurements. We need to know how the central nervous system metabolism of indoles relates to the peripheral elevation in the blood. We have major difficulties interpreting the platelet serotonin abnormalities. (For details, see Reference to special issue, June 1982, Journal of Autism and Developmental Disorders.)

Genetic and congenital factors have repeatedly been suggested in autism. Twin studies and increasing numbers of reports on mutiple familial occurrences have supported the hypothosis. The best study, to date, identifying 21 twin pairs of nonidentical twins concordant for the diagnosis. Siblings of autistic patients have a fifty-fold greater (than the general population) chance of being diagnosed as autistic. How many are "atypical" or "Asperger's" cases is as yet unresearched. The conclusion reached by Folstein and Rutter (1977) cautioned us that the inherited trait may be for a broader cognitive disability than for diagnosable core autism **per se**. A search for the spectrum of cognitive and social impairments in the family of autistic probands is currently being planned.

The other genetic factor which has received a great deal of recent attention is that of the Fragile-X syndrome. However, although there have been recent case reports now adding up, to my knowledge, to perhaps a dozen persons called autistic who have the Fragile-X abnormality associated with the autistic syndrome, we are not yet in a position to give genetic counseling about risks to affected families, due to the fact that the Fragile-X has been reported in perfectly normal males as an incidental finding to work up for fertility problems, in slightly symptomatic or mildly retarded females, thus raising questions about exactly what the mechanism of chromosomal-genetic transmission would be, and the fact that the overwhelming majority of persons reported to have the Fragile-X are mentally retarded without any of the signs of the general diagnostic criteria for autism, namely impaired social relationships, delayed/deviant language development and stereotyped or ritualistic behavior. In fact, there appears to be quite a spectrum of abnormalities associated with the Fragile-X syndrome and the finding itself is an unstable one which has not yet been established to occur in newborns, to stay stable through life, and in fact in female carriers actually may be a disappearing phenomenon as the females age! All this is submitted as a cautionary note so that the Fragile-X syndrome and its relations to autism will be kept in its proper perspective as exciting but still quite preliminary.

Electrophysiological abnormalities ranging from brainstem auditory-evoked potentials through the P300 late components at the critical level have been reported to be abnormal particularly with respect to auditory perceptual input in autistic children. An important observation and theoretical formulation by Dr. Tanguay indicates that distortions in auditory perception may be present during a critical phase of early postnatal childhood development and act again in a brain-to-brain active neuropathological ontogenetic factor. In other words, the brainstem auditory evoked response findings may have nothing currently to do with what is wrong with the autistic child but that the brainstem dysfunction had lead to earlier distortions in the forebrain's auditory stimulation, resulting in language, social and cognitive handicaps in the child's development of normal neuro-connections which we know to be profoundly influenced by both visual and auditory input. Tanguay has referred to this hypothesis as "the whisper of the bang"—referring to the phenomenon that the uniform background radiation in the universe appears to be the "residual whisper" from the presumed "big bang" that marked the beginning of the universe ten to twenty billion years ago! This is something to be kept in mind when we look at reported abnormalities in vestibular, auditory, or any relatively subcortical area that we are looking at something which once was although it may not currently be important in the development of the syndrome. Some researchers have attempted to relate abnormal brainstem auditory evoked responses to the peculiarities of attention ("stimulus over-selectivity") seen in autism.

The other important point to be kept in mind in the search for localization or etiology in the chemical, viral, or genetic sense for autism is that the children do not look all uniformally neurologically the same in spite of the fact that they share the common diagnostic features. This lecturer has been impressed by the "basal ganglia" appearance of large groups of adults and adolescents who are in the facilities for autistic persons but has seen extremes such as some persons who have involuntary movement disorders reminescent of Huntington's disease while others at the other end of the spectrum appear to have the stooped posture and hypomobility characteristic of the Parkisonian patient. Again, Maurer and Damasio have restated their analysis of the abnormalities present in autistic patients using standard clinical-pathological inferential methods of reasoning and have come to the conclusion that the phylogenetically older cortex located on the mesial surface of frontal and temporal lobes, the striatum, and the thalamus are our "best bets" in terms of places in which to look for the effect of or the manifestations of viral or chemical abnormalities, since selective infectious and selective neurotransmitter abnormalities within parts of the nervous system are certainly well-established neurological phenomena.

Thus we must conclude that in dealing with autism and related disorders we are dealing with a group of related disorders which have in common the production of certain symptoms not identical in every case based upon probably widely varying etiologies. It is therefore not surprising that there is very little uniformity in terms of the utilization of medications. Generally speaking, the treatments with the major phenothiazines and butyrophenones has been somewhat more sucessful than treatment with the stimulants, but no one has proported to have found a particular specific cure. Since 1982 fenfluorimine has been reported to be beneficial in some autistic boys, lending further interest to the serotonin hypothesis. To date, 14 patients have been studied; some showed no improvement, while the group as a whole showed social and communicative improvements (but not IQ improvements). Younger children made greater social gains on fenfluoramine. A double-blind study of 150 autistic patients (at 18 centers) is about to begin.

There also has been interest in using vitamin therapies; and although enthusiasts for vitamin B6 exist on both the East and the West coasts of this country, again the heterogeneity of both symptom-complex and etiologies has not lead to a very great concensus on this point.

The greatest concensus which exists is that behavioral and (where appropriate because of higher functioning) behavioral-cognitive therapies are the most effective ways of treating autistic children. There has been widespread abandonment of the psychodynamic and conventionally analytic or insight-oriented therapies in favor of a didactic, educational approach. With the lower IQ groups, a strictly behavioral approach to eliminate self-abuse and mal-adaptive behaviors and to reward for a more adaptive behavior such as eye contact and attempt at verbalization have been successful. With the higher-functioning individual such as with Asperger's syndrome, there has been considerable success with a behavioral-cognitive approach in which some degree of generalization from one situation to another is possible, but even here there is a startling lack of ability to generalize in the high-functioning person with autism.

Reference List

for "New Concepts of Autism"

(note: order of mention is from most to least recent)

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The Vocational Rehabilitation System

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The Vocational Rehabilitation System

Peter Griswold

As a director of a state rehabilitation agency, it is always a pleasure to present our program at conferences and meetings. Since I was a member of the Planning Committee for this conference, I am honored to discuss rehabilitation services with such a distinguished group. What I will do is to present a general overview in order to allow ample time for questions you may have.

The State/Federal program is comprehensive and complex. It is not a new program, but began in 1920, and has expanded its services to new populations with each succeeding legislation. While we have served individuals with autism in the past, we may not have done so effectively, and as a consequence, state directors welcome this opportunity to meet with advocates and professionals in the field of autism to construct a responsive service system.

The State/Federal Partnership

The state/federal vocational rehabilitation program exists in all 50 states and Washington, D.C., as well as in the United States' territories. The Rehabilitation Services Administration (RSA) in the federal Department of Education implements rehabilitation legislation. Each State submits an Annual Plan to RSA which serves as a contract with the federal government to qualify for federal financial participation. The major source of funding is 80% federal monies, which are matched with 20% state funds. An additional source of funds is cash match agreements with agencies in local communities to supply the state's portion of matching funds in order to receive all available federal funds.

At the state-level rehabilitation agency, persons are served on an individual basis by a rehabilitation counselor. This relationship takes place at the state agency district office nearest the handicapped person's home with counselors available to meet clients at any mutually convenient location. In other words, rehabilitation services does make house calls. It is to be remembered the vocational rehabilitation program is an eligibility, not an entitlement, program. Persons who apply at their local state office must meet these criteria: The person must have a physical or mental characteristic that interferes with the ability to earn a living. There must be a reasonable chance that the person will become employed if rehabilitation services are provided.

There is no upper or lower age limit for agency services, but because the goal of rehabilitation is employment, rehabilitation counselors generally begin working with handicapped youth during their last few years in high school. For persons of advanced age, counselors do need to establish that the individual can be expected to maintain employment for a reasonable period of time. The disabilities served by the program range from physical handicaps, such as cerebral palsy and diabetes, to mental conditions, such a drug addiction and mental illness, as well as mental retardation. In some states there are two agencies, one for the blind and one for all other categories, commonly called the "General Agency."

In the process, all applicants are afforded a diagnostic study, which includes an appraisal of their current health, to determine: Whether the individual has a physical or mental disability which constitutes a substantial handicap to employment, and whether vocational rehabilitation services may reasonably be expected to assist the person into employment. In many cases a period of extended evaluation of up to 18 months is needed in order to determine eligibility for rehabilitation. This is to afford persons who are severely disabled every opportunity to demonstrate potential.

Diagnostic studies may include one or more of the following:

1. General medical examination
2. Medical specialty examination
3. Psychological evaluation
4. Social evaluation (to note family, community support)
5. Assessment of educational achievement
6. Vocational evaluation
   a. may provide information on a client's aptitudes, skills, capacities, physical and mental limitations, and tolerances.
   b. is usually obtained from a rehabilitation facility but also may be obtained from an employer or educational institution.

To proceed with the planning, a vocational goal must be decided upon by the client and counselor.

1. The goal must be appropriate based on such factors as client's aptitudes, interests, physical capacity, previous employment, and educational achievement.
2. Job availability, labor market trends, client's ability to relocate, and required wages are also a consideration.
3. The goal selected in many states must be expected to result in weekly earnings equal to no less than 20 hours at the current minimum wage.

Employment options for clients include:

1. Competitive employment in the open job market which may include supported employment
2. Practice of a profession
3. Self-employment
4. Homemaking
5. Unpaid family worker
6. Homebound employment
7. Sheltered employment — Sheltered employment may be the vocational goal for clients who are unable to enter the competitive work force due to:
   a. severity of disability, or
   b. inadequate personal adjustment
8. Work Activity (This is allowed in some states, but many consider work activity as therapeutic or recreational and not an employment outcome from rehabilitation services.)

As mentioned earlier, federal rehabilitation requires that an individualized written rehabilitation program (IWRP) be developed by the counselor with each client or his or her parent or guardian. This IWRP must be developed for each person who is eligible for services and for those on extended evaluation. It contains:

1. vocational goal (except for extended evaluation).
2. objectives and services necessary to achieve the vocational goal and the availability of services from other agencies.
3. anticipated begining data and duration for each service.
4. a procedure for evaluating progress toward achievement of objectives.
5. client's comments and a statement of client rights.

Clients and/or appropriate family members are asked to participate and contribute to the extent they are able in the cost of the rehabilitation program. An economic needs test is not a condition for receiving services in many states. It is a state option except for training when state or federal financial aid is available, such as student financial packages.

Agencies are required, however, to seek out similar benefits to use to supplement rehabilitation funds. A lot of time and effort is required to coordinate eligibility and access a number of programs, but it does augment the case service dollar.

Vocational rehabilitation services are provided to assist the client to prepare for a job, find a job, and, when needed, maintain a job. Services that are available include:

Vocational counseling provided by qualified counselors to assist each client in achieving the vocational goal. This is provided at no cost to the client by the agency.

All **diagnostic evaluations** needed to establish eligibility and select a goal.

Physical and mental restoration services needed to remove or reduce a limitation that affects the employability of the client. For example:

1. surgery
2. treatment and medications
3. physical therapy
4. prosthetic devices
5. hearing aids
6. wheelchairs
7. speech therapy

Interpreter services for deaf clients or for clients who speak a language other than English.

Job training through adult education; trade, technical, or business school; college; or provided on the job.

Costs of meals, lodging, and transportation to support the client's participation in a vocational rehabilitation program.

The purchase of **equipment, licenses, and tools** in order for the client to begin work.

Job placement assistance provided by the counselor to enable the client to go to work—the goal of the vocational rehabilitation program through the following programs:

a. Job-seeking skills clinics
b. Job clubs
c. Employment leads matching jobs banks to skills banks
d. Direct job referrals

In the rehabilitation process, clients are informed of their rights and responsibilities. Clients and client applicants to the vocational rehabilitation program have rights under the law, which are:

1. Citizens have a right to an evaluation of their eligibility.
2. Eligible persons have a right to an Individualized Written Rehabilitation Program and to participate in its development.
3. Clients may review information in their case file with the exception of highly technical medical and psychological reports.
4. Clients have a right to confidentiality.
5. Clients may appeal state agency actions concerning the services denied or provided to them.

Clients also have responsibilities that are necessary to a successful vocational rehabilitation.

1. Applicants must cooperate in providing information the state agency may need to determine eligibility or to develop a rehabilitation program.
2. Clients must keep scheduled appointments with physicians and others involved in the program.
3. They have a responsibility to help pay for part of the costs of their rehabilitation program to the best of their ability.
4. They have a responsibility to cooperate in using other community services when these can be of help in the program.
5. Clients in training have a responsibility to perform satisfactorily and attend regularly.

In describing the State/Federal Program, it is important that we note its economic value to society. The Rehabilitation Services Administration reported in 1982 that the state/federal rehabilitation program is highly cost-beneficial to the persons it serves. The estimated life earnings for persons rehabilitated in FY 1980 will improve by $10.40 for every one dollar spent on services for all clients whose cases were closed in that year. This was the fifth consecutive year for which the projected cost-ratio has been greater than $10 to $1. The RSA study also showed that, in the first year after case closure, persons rehabilitated in FY 1980 are expected to help pay the federal, state, and local governments an estimated $211.5 million more in income, payroll, and sales taxes than they would have paid had they not been rehabilitated. In addition, another $68.9 million will be saved as a result of decreased dependency on public support payments in institutional care. The $211.5 million and $68.9 million provide a grand total first year benefit to governments of $280.4 million. At this rate, the total governmental benefit will equal the total federal, state, and third-party cost of rehabilitation for FY 1980 closures in four years.

The Scope of the Program

In FY 1983, nearly 1 million persons were served by all state rehabilitation agencies (938,923). Three-fifths were severely disabled.

Of those served, 216,231 persons were rehabilitated into employment. Fifty-seven percent were severely disabled.

Federal support of the state/federal vocational rehabilitation program is now over $1 billion.

Advantages of State/Federal Rehabilitation

1. It is the nation's largest, best funded civilian service program for persons with disabilities.
2. There is a long and rich tradition of service, which is cost-effective, well managed and clearly accountable to the public.
3. It is a prime example of public and private cooperative ventures.
4. Rehabilitation closely allied with consumers, advocates, and community rehabilitation agencies.
5. It provides a flexible service designed to meet the individual needs of clients.

6. It is part of a support network provided by national and regional offices who assist in funding research and training centers, continuing education programs in rehabilitation and independent living centers as well as grants for facilities, inservice training, technical assistance, and monitoring.

7. The rehabilitation program incorporates consumer supervision through the National Council for the Handicapped, state consumer advisory councils, local business and allied agency councils, and a Client Assistance Program.

8. Agencies assure client rights through a fair hearing process.

9. Rehabilitation agencies possess a skilled cadre of rehabilitation counselors and managers through intensive pre- and post-service training.

10. It is involved with all aspects of the community—political, educational, legal (worker's compensation), social services, medical, independent living centers, social security, allied health agencies, consumer organizations, business and industry. It is often the only agency that has contacts with all of the above agencies and/or organizations.

11. Rehabilitation has a federal program which allows states an ability to tailor their program to their needs within a broad framework of the Rehabilitation Act.

Current Disadvantages

1. There is a need and demand which outstrips human and fiscal resources.

2. Programs may vary in comprehensiveness by widely ranging state level support—medicaid, etc.

3. They may also vary on emphasis by agency location in state structure—Department of Labor, Education, Social Services, separate department.

4. The skill level of counselors may vary by availability of trained work force, level of pay, turnover, agency philosophy.

5. Rehabilitation is effective only to the extent that the community has support services available—transportation, housing, barrier-free environment, education and training programs, medical and psychological services, available employment. This point is particularly germane to serving persons with autism.

Let me conclude my presentation by stating that service to individuals with autism is entirely possible through the state rehabilitation agency, but there is much to do before we can be fully effective.

For this we must establish common values. Decision making in the process must involve all interested parties and collaborative ventures must be undertaken to demonstrate the effectiveness of service.

Advocates and professionals concerned with autism must assist state programs in finding appropriate financial support and assist in training counseling staff.

Above all, we need leadership from the national, state, and local levels if we are to achieve a common goal, i.e., of providing more effective services to individuals with autism.

Critical Dimensions Of Non-Sheltered Employment Models

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Critical Dimensions of Non-Sheltered Employment Models

Marcia Datlow Smith, Ph.D

The achievement of non-sheltered employment by persons disabled by autism has been and can continue to be a reality given adequate performance on a number of critical dimensions. Community Services for Autistic Adults and Children in Rockville, Maryland has been assisting persons severely disabled by autism in the achievement and maintenance of nonsheltered, paid employment for the past five years. In a review of the procedures and methods employed in this effort, including consideration of the problems encountered and the solutions, the following dimensions stand out as being critial to the success of a nonsheltered employment model.

Adequate Process for Determining What Support is Needed

Autism is a disorder which encompasses a complex set of symptoms, strengths and weaknesses. Persons disabled by autism can vary greatly in their presenting problems, as well as in their skills and abilities. Although any one individual who has autism might have his/her needs met by addressing one critical problem or symptom area, this approach can not be used uniformly for all persons with autism. To account for the complexity of the disorder, a multi-dimensional approach must be taken in order to determine necessary support. Two examples will illustrate why the process for determining support cannot be unidimensional.

One cannot assume, because a person disabled by autism has a particular strength, that supportive services can be reduced accordingly. For example, a primary area of deficit associated with autism is speech and language. Langauge may be present and fluent, it might be present to an extent, or it might be totally absent. However, the amount of support a person might need on the job cannot be solely determined on the basis of speech and language proficiency. And, in fact, good language does not necessarily indicate that less support is needed than in cases of poor language. For example, it is possible for a person disabled by autism, Client A, to be fluent in language, and yet have severe problems with self-injury and aggression, thereby requiring high levels of sophisticated support. On the other hand, Client B has no expressive language at all, but can understand instructions, has virtually no behavior problems, and performs a job with less support than Client A, whose language skills are far superior.

Mental retardation is often associated with autism, but again, one cannot make blanket assumptions about the amount or type of support that a client with autism needs based on intelligence level as measured by standardized intelligence tests. For example, the intelligence of Client C measures in the mentally retarded range, but this client has fairly good communication skills, can engage in short conversations, greets others and follows explicit instructions fairly well. The intelligence of Client D measures in the superior range. However, he will not communicate verbally in job or social situations, and engages in calculating difficult math formulas to the exclusion of job assignments. Client B, because of his communication difficulties and lack of motivation to perform on the job, requires more support in the job than Client A, despite his significantly higher intelligence level.

These two examples illustrate the challenges presented in determining support systems for persons disabled by autism. Strengths in critical areas do not preclude a need for extensive support because of the possiblity of weaknesses in other areas. Although challenges are presented by the complex nature of the disorder, an interdisciplinary team, taking a multi-dimension approach to diagnosis and the planning of support services would be capable of providing an adequate process for determining what support is needed. The adequacy of this process is critical to the success of the nonsheltered employment experience.

The Provision of Adequate Support

Once a determination is made on the type and amount of support needed for vocational success, it is critical that this support be provided. The difficulties associated with autism can be job threatening, and the failure to provide adequate support at the outset could result in a failed experience for the client, the service provider and the employer. It is most likely more effective in the long run to provide ample services at the outset, and only phase out these services as success is demonstrated, than to provide inadequate support with crises-instigated increases which might be too little, too late.

Agency Support for Use of Support

Supportive services necessary to insure employment success of persons disabled by autism could include recommendations from a psychologist, special educator, speech and language therapist, nutritionist, occupational therapist, or physician, to name a few. These recommendations might be made to the agency providing direct services to the client; then the agency takes on the responsibility for implementing recommendations. It is critical that the agency be committed to accepting, processing and implementing the recommendations of consulting professionals, especially as these recommendations bear on vocational success.

Treatment plans of consultants, in some agencies, may or may not actually be implemented. In a nonsheltered setting, if the recommendations are not implemented, the consequences of non-implementation may have no particular effect on the client. However, failure to implement recommendations in a nonsheltered place of employment could result in the client losing his/her job. Client A has difficulty accepting instructions. When Client A resided in an institution, if given an instruction, he would shout and flail his arms. A treatment plan is developed, inconsistently implemented, and the behavior persists. In any case, Client A goes about his life on his ward. However, Client A leaves the institution, moves into a group home and is placed in a job at the local department store. Accepting instructions is still a problem for this client. A treatment plan is developed. If the plan is implemented, the client will learn a more acceptable way of responding to the delivery of instructions. If the plan is not implemented, the client runs a high risk of being fired.

Many of the behavioral difficulties associated with autism, such as self-stimulatory behavior, aggression, self-injury, failure to stay in assigned location (i.e. to wander off), lack of social skills and off-task behavior, if left untreated, are job threatening. It is critical to the success of the nonsheltered employment model that adequate support not only be prescribed and available, but that such support be fully provided to the client.

Optimistic Problem Solving Process

Problems associated with autism might seem overwhelming in nonsheltered settings. However, the providers of a nonsheltered employment model to persons disabled by autism need to expect that job-threatening behaviors or circumstances might develop, and a support system with an optimistic problem solving process needs to be in place to efficiently solve these problems and maintain nonsheltered employment. If the standard reaction to an apparently job-threatening problem is to terminate employment or change worksites, then one might find in time that there are no worksites left to move to. However, if a problem solving process exists which systematically identifies the problem, designes a solution and implements solutions, then the client might ultimately make an adjustment to the work setting in which the problem presented. Failure to attempt to solve problems in the setting as they come up limits the employment options of the client both in that setting and in the job market in general.

The necessity of an optimistic problem solving process can best be illustrated through the example of Client E. Client E had a history of verbal abuse towards others—kicking, spitting and knocking into objects and people, occasional instances of aggression towards people and frequent refusal to follow instructions. In fact, Client E had been terminated from a sheltered work setting because of these behaviors. On her first day in a nonsheltered work setting, Client E began to kick at boxes, spit on the floor and refuse work. A problem-solving process immediately went into effect aimed at increasing the client's productivity and decreasing the frequency of the job-threatening behaviors. A behavior management specialist observed the client at work, designed a treatment plan and trained the client's vocational counselor in the implementation of the treatment plan. Through consistent implementation of the treatment plan, the client's social skills increased, social problems dramatically decreased and productivity doubled within two weeks. An optimistic problem solving process was critical for serving this client in a nonsheltered setting, as well as for serving any client disabled by autism.

Reliance on Principles of Learning and Positive Reinforcement

For many persons disabled by autism, simply providing a counselor in the job setting to supervise their work or monitor their behavior will not suffice to achieve a successful work experience. The counselors need to be trained in methods for teaching specific work skills to the client, as well as in strategies for teaching alternative acceptable behaviors to replace any behavioral difficulties which may arise. Given these strategies, the counselors can then provide the support necessary to learn the vocational and social requirements of the job.

Motivation of good work behaviors is especially critical, particularly since some clients may not be motivated by money, even though they are earning wages. In those cases, it is important that motivators be provided which are meaningful to the client. And, although money itself may not be a motivator, it is helpful to keep in mind that often, the things that money can buy will motivate a client. Additionally, the worker with autism may be motivated by some of the same things that motivate persons without autism, namely, the status of having a job, the opportunity to perform the work, the social esteem which accompanies the job and social relationships which are formed on the job.

Teaching strategies and behavior management strategies can be implemented both nonaversively and unobtrusively in nonsheltered employment settings if these strategies are based on principles of learning and the principle of positive reinforcement. Individualized teaching strategies, maximizing use of coworkers as models and fair systems of motivation can combine to make the work experience successful for the client disabled by autism. The ability to develop, coordinate and implement these strategies at work is a critical component of a nonsheltered employment program for persons disabled by autism.

Community-Integrated, Supportive Residential Situation

A nonsheltered employment model provides for clients to go to work and work, hopefuly as independently as possible, alongside nonhandicapped co-workers. A critical dimension of a nonsheltered employment model is the supportive existence of a residential program for the clients which stresses self-reliance, and active participation in home and self care activities.

Many persons with autism have been served and are served in residential settings in which active participation in their schedule and self reliance are not primary goals. Rather, situations often exist in which the person with autism is the passive recipient of basic self-care activities, and little or no community-integrated activities are conducted. If a client is expected to work at a job for eight hours, then a residential situation must exist which supports these expectations.

The residential setting must support the vocational setting by teaching self-reliance, active participation in the environment and interactive skills. A client who at home can help plan and prepare meals, wash his/her own clothing, help maintain self and house and who has ample opportunity to interact with others in the home will most likely more easily adapt to a nonsheltered work setting than a client who at home is the passive recipient of services from caretakers, with no expectation of active involvement. Further, the opportunity to spend the fruits of one's labor in recreational and leisure activities outside the home may be a critical motivational component in maintaining steady work behavior.

A Supported Work Approach To Competitive Employment of Individuals With Moderate And Severe Handicaps

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Abstract

The purpose of this paper is to discuss how a supported work approach can improve the competitive employment opportunities for moderately and severely handicapped people to include those with autism. In this paper we emphasize the importance of competitive employment and describe the four major components of a supported work approach to nonsheltered employment. These are: job placement, job-site training, on-going assessment, and job retention. Also discussed are specific proposals for integrating a supported work system into sheltered workshops, community service programs, and secondary special education programs. A major conclusion of this paper is that significant policy and service delivery changes are necessary in order to overcome the extraordinarily high rate of unemployment among moderately and severely handicapped people.

A Supported Work Approach to Competitive Employment of Individuals With Moderate and Severe Handicaps

Janet W. Hill

Individuals who are severely handicapped do not participate in the workforce to the same extent as nonhandicapped citizens. Today, despite improved public awareness of the rights of severely handicapped persons and significant increases in the number of day programs for adults (Bellamy, Sheehan, Horner, and Boles, 1980), hundreds of thousands of potentially employable individuals remain idle. Unemployment rates of 50 percent to 75 percent (U.S. Commission of Civil Rights, 1983) and average annual wages of $414 for retarded workshop clients (Whitehead, 1979) provide a dramatic description of the current deplorable state of affiars. Failure to incorporate persons with moderate and severe handicaps into the labor force wastes a valuable human resource. The cost of dependency in terms of public income maintenance and other forms of assistance places a tremendous strain on our nation's economy. Even greater are the human costs of idleness and dependency on the lives of severely handicapped people.

Research and demonstration along with other activities during the past 10 years have resulted in significant improvements in the vocational training and placement of persons with severe handicaps. Early emphasis was placed almost exclusively on training severely retarded and multiply handicapped individuals to perform sheltered work tasks (Bates, Renzaglia, & Clees, 1982; Bellamy, Peterson, & Close, 1975; Gold, 1972; Hunter & Bellamy, 1977; O'Neill & Bellamy, 1978; Wehman, Rengazlia, Bates, & Schutz, 1977). Recently, additional efforts have been directed toward training and placing severely handicapped workers into less sheltered or nonsheltered settings which focus more on competitive employment.

For example, several investigators have reported success with job placement, job site training, and follow-up of moderately and some severely retarded clients. Sowers, Connis, and Thompson (1979) described the placement results of the University of Washington Food Service Training Program which has clearly been one of the forerunners in this area. This program continues in a successful manner. In a similar vein, Kraus and MacEachron (1982) published the results of the Transitional Employment program for mentally retarded persons. In this report, it was found that participants' work behavior, ability to meet job requirements, and wages were predictors of competitive placement. Brickey and his colleagues (Brickey & Campbell, 1981; Brickey, Browning, & Campbell, 1982; Brickey, Campbell, & Browning, 1983) have also done an excellent job of placing, training, and tracking mentally retarded graduates of sheltered workshop programs. Brickey's work, in particular, highlights the cost-effective features of sheltered workshop programs that provide regular and systematic follow-up of placed clients. In Vermont, Williams and Vogelsburg (1980), have been active in demonstrating the competitive employment capabilities of moderately and severely handicapped workers in nonsheltered settings. Over 40 clients, primarily from adult day programs, have been successfully placed in the last two years.

In our own work over the past five years we began with simple case study demonstrations (e.g., Wehman, Hill, & Koehler, 1979) and have since moved to benefit cost analysis of our placed clients (Hill & Wehman, 1983) as well as an on-going follow-up of client progress (Wehman, Hill, Goodall, Cleveland, Pentecost, & Brooke, 1982; Wehman, M. Hill, J. Hill, Brooke, Ponder, Pentecost, Pendleton, & Britt, 1984). To date, over 150 clients have been placed into competitive employment and approximately 55 percent are still working. The median measured intelligence quotient of those clients was 47 with the majority being labeled moderately mentally retarded. Kochany and Keller (1981) have described some of the reasons our clients fail to maintain employment. Major reasons include parental dissatisfaction, transportation breakdowns, client maladaptive behavior, and changes in employer policies. In addition, some clients move away or simply wish to change jobs after a period of time.

Competitive employment is usually superior to placement in any type of sheltered work environment. It offers the possibility of dramatically improving an individual's lifestyle while resulting in tremendous financial savings for social service agencies. Competitive employment allows persons with moderate or severe handicaps to earn significant wages and receive fringe benefits not available to workers in sheltered settings. The work performed in competitive environments is often more meaningful and challenging to the individual. It also offers the greatest opportunity for long-term job retention and advancement. Competitive jobs are usually not affected by lack of available work or the seasonal variability that often plague sheltered work programs. Perhaps most important is the ability of competitive employment to facilitate the integration of severely handicapped individuals into all facets of community life. Opportunities to travel more independently, utilize retail environments, and develop friendships with nonhandicapped coworkers are greatly enhanced for individuals working in the competitive sector.

Competitive employment also possesses a number of other significant advantages. It can lead to improved perceptions of handicapped workers by parents and policymakers. If parents become convinced that their children can succeed in competitive employment and make a meaningful wage, they may be more likely to take the major risks involved in working out transportation problems, overcoming Supplemental Security Income (SSI) disencentives, and providing support to their sons or daughters. Policy makers are more likely to be impressed by vocational training efforts which result in placement in competitive employment. It is unreasonable to expect legislators to continue to provide millions of dollars annually to support programs which result in workers making a few dollars a week. Competitive employment placements are most persuasive in seeking greater funds for continued job placement efforts. The benefit cost analysis data of Hill and Wehman (1983) strongly suggest that competitive placement programs can actually result in long-term savings to taxpayers.

What we need to know, however, is the best way to place and retain moderately and severely handicapped individuals in competitive employment. It is evident that the traditional model of placement with no intensive job-site training and follow-along does not work for most moderately and severely handicapped people. Our experiences as well as those of many other investigators referenced earlier document this fact along with the reality of thousands of severely handicapped people not receiving access to rehabilitative services because they are not deemed to be "employable".

In this paper we will present a model which has worked effectively for almost six years. We call it supported work because clients receive staff support in differing degrees of intensity and depending on their unique needs. A detailed description is provided of how supported work can be applied to improving competitive employment opportunities for moderately and severely handicapped people who typically have been unemployed in society. It is important to note that supported employment can refer to other approaches to facilitating paid work for severely handicapped persons. For example, a recent U.S. Dept. of Education, Office of Special Education and Rehabilitative Services initiative (1984) characterizes supported employment as paid work which usually occurs in regular work settings. It may involve competitive employment but might also involve sheltered enclaves, mobile work crews, sheltered industries or other creative approaches to improving employment opportunities. The critical aspect of this U.S. Dept. of Education initiative is the focus upon the historically or chronically unemployed severely handicapped population.

The Supported Work Model

A supported work approach to competitive employment involves highly structured job placement, individualized training, and job retention of clients with moderate and severe handicaps. It is characterized by intensive job-site training in integrated, community-based employment settings. The model is applicable for use with large numbers of individuals who have had limited previous exposure to competitive work environments. It can be successfully implemented by public school and community service programs in both urban and rural areas. The supported work model contains four major program components: (1) a comprehensive approach to job placement; (2) intensive job-site training and advocacy; (3) ongoing assessment of client performance; and (4) a systematic approach to long-term job retention and follow-up. The following Checklist summarizes the principle components and associated characteristics of the supported work model.

Although it is probably not necessary for all handicapped persons, the supported work model is suitable for use with large numbers of handicapped individuals in both public school and community service programs. The model is generally intended as an alternative vocational outcome for persons unable to succeed or gain entrance to traditional public school work-study programs or monitored employment programs operated by rehabilitation facilities. Within public school settings, these individuals are usually served in programs for students labeled moderately mentally retarded or, in a few instances, mildly mentally retarded. Individuals labeled severely mentally retarded or multiply handicapped will also be prime beneficiaries of this approach although we have less data focusing exclusively on this population. Within community service programs, the model may be applicable to persons who are usually labeled by rehabilitation facilities as possessing severe disabilities and who are most frequently served in sheltered workshops or activity centers.

The supported work model possesses several key features that distinguish it from other approaches to job placement. In contrast to less intensive job placement approaches such as the "job club"(Azrin & Besalel, 1980) or selective placement (Rubin & Roessler, 1978), the suported work model relies on a comprehensive approach to job placement that actively deals with the non-work related factors which often stand as barriers to employment, i.e. parental concerns. Another key difference between a supported work approach and other approaches is its extensive application of job site training and advocacy procedures. This emphasis allows clients to be placed who do not possess all the necessary work or social skills required for immmediate job success. This represents a significant departure from traditional placement approaches that require the client to be "job ready" before placement can occur and alternative approaches that train a client to a specific level of mastery within a training environment prior to a final placement.

Other distinguishing features of the supported work model are its commitment to **long term** assessment of client performance and delivery of job retention and follow-up services. In sharp contrast to rehabilitation programs that typically provide follow-up services for several months, clients within the supported work model may receive systematically planned job retention and follow-up services for many years after initial placement. Finally, the supported work model is perhaps unique in its identification of a single "job coordinator" who is responsible for all facets of the placement, training, advocacy, assessment, and follow-up process. Rather than utilizing professional staff who specialize in a single aspect of the placement process, reliance upon a job coordinator greatly enhances continuity across all phases of the placement and follow-up process.

In the remainder of this section, we will discuss the four major program components of the supported work model in greater detail. Each component (placement, job site training and advocacy, ongoing client assessment, and job retention and follow-up) will be defined and illustrations will be provided to demonstrate the applicability of the model to public school and community service programs.

Checklist of Activities in Supported Work Approach to Competitive Employment

Program Component I:	**Job Placement**	• structured efforts at finding jobs for client and matching client strengths to job needs • planning of transportation arrangements and/or travel training • active involvement with parents on identifying appropriate job for client • communication with social security administration
Program Component II:	**Job Site Training and Advocacy**	• trained staff provide behavior skill training aimed at improving client work performance • trained staff provide necessary social skill training at job site • staff work with employers/coworkers in helping client • staff help client and coworkers adjust to each other
Program Component III:	**On-going Assessment**	• provides for regular written feedback from employer on client progress • utilizes behavioral data related to client work speed, proficiency, need for staff assistance, etc. • implements periodic client and/or parent satisfaction questionnaires
Program Component IV:	**Follow-up and Retention**	• implements planned effort at reducing staff intervention from job site • provides follow-up to employer in form of phone calls and/or visits to job sites as needed • communicates to employer of staff accessibility as needed • helps client relocate or find new job if necessary

Program Component I: Job Placement

The placement of the client into a job appropriate to his or her abilities is the first major component of the supported work model. A great deal has been written about job placement (e.g. Goodall, Wehman & Cleveland, 1983; Vandergoot & Worrall, 1979). However, we believe that the process of job placement involves more than simply finding a job for a client. Major aspects of the job placement process include:

1. A comprehensive assessment of job requirements and client abilities which results in an appropriate **job match**:
2. An **active** approach to handling non-work related factors such as travel, social security, and caretaker support.

The placement process begins by surveying the community labor market to identify the types of jobs that appear likely to have vacancies or high turnover rates and which appear to be within the capacity of potential clients. After specific jobs have been identified, an accurate analysis of work environment requirements must be completed. This process has been variously referred to as ecological analysis (Wehman, 1981), top-down curriculum (Brown, Branston-McClean, Baumgart, Vincent, Falvey, & Shroeder, 1979), or job analysis (Vandergoot & Worrall, 1979). It is critial that adequate detail be provided in terms of job requirements, characteristics of the work environment, and other features which may influence job retention.

Initial client assessment is conducted concurrently with the job development and analysis activities. A multifaceted approach to client assessment is employed. Information is obtained concerning client adaptive behaviors, parent/caretaker attitudes, transportation possibilities, the client's expressed willingness to work, and other relevant factors. In addition, the assessment will determine the client's current ability to perform some of the vocational skills that may be required in the targeted job areas. **An inability to perform a large number of these skills does not preclude a client from placement, since a major strength of the supported work model is its ability to place individuals who do not possess all the work skills needed for immediate job success.** However, if the client has not received at least a minimal amount of training through a pre-employment vocational program, the placement and retention process will take a great deal more time and, in the long run, will be more costly to the agency providing the service.

The results of work environment analysis and initial client assessment can be used to determine an appropriate job match. For example, how many of the skills required by a particular job is the client currently able to perform? This information can be used to project the amount of staff time that may be required during the early stges of employment. If a client is being considered for a position on an evening or weekend shift, how will the client get to and from the job? Public transportation may be limited at these times, and alternative transportation arrangements may be required before placement can occur. It is also important to consider whether the client has expressed interest in the type of job under consideration. Our experience has shown that handicapped workers often have strong job interests and preferences. Placements made without regard for a client's expressed interests will frequently fail after a short period of time. These examples illustrate the necessity of matching both job requirements and client characteristics to ensure successful placements.

The second major aspect of the job placement process in the supported work model involves an **active** approach to handling non-work-related factors such as travel, social security, and caretaker support. Within a more traditional placement framework, it is often accepted that the client or caretaker will handle most of these concerns if a job is made available. For persons with moderate or severe mental handicaps, job placement would be impossible or highly unlikely without this type of support. Arranging for alternative forms of transportation to and from work, assisting the client in dealing with changes in social security status, and adddressing the natural fears of concerned parents requires the active involvement of a trained professional. In many instances, effective handling of non-work-related factors will make the difference between a successful and an unsuccessful placement.

Program Component II: Job Site Training and Advocacy

As noted earlier, on-the-job training is certainly not a new concept. However, in most employment models, a trained professional is not available early in the placement to actively intervene on behalf of the client. Employers are often viewed as solely responsible for training the client. Frequently, no specific training is provided. Instead, brief and infrequent followup checks or visits are made for a short time after the initial placement. In short, two major steps in the placement process are omitted, namely, specific skill training and adjustment to the work environment.

Our experience in placement and our communication with others using a supported work model strongly indicate that job site training and advocacy are essential features of the model. Job site training refers to direct instruction provided by a trained professional enabling the client to perform all skills required by the job. Advocacy involves noninstructional intervention on behalf of the client. Both job site training and advocacy are necessary to promote the client's initial adjustment to the work environment and long-term job retention.

Application of behavioral training strategies to vocational skills in nonsheltered or competitive work environments has received relatively little attention by researchers. Rusch has clearly been the leader in this regard with studies related to acquisition of selected work skills (Schutz, Joste, Rusch, & Lamson, 1980), time-telling (Sowers, Rusch, Connis, & Cummings, 1980), time on-task on the job (Rusch, Connis, & Sowers, 1980), reducing inappropriate self-stimulating behaviors (Rusch, Weithers, Menchetti, & Schutz, 1980), and selected communication training (Karlan & Rusch, 1982). It is apparent to us that the technology of behavioral training needs to be extended into nonsheltered work environments with individuals who heretofore have been considered poor candidates for competitive employment. We have barely begun to scratch the surface in this area. Applications of reinforcement principles, manipulation of antecedent stimulus conditions, and use of coworkers as peer trainers are all areas which require closer investigation.

Advocacy, or noninstructional intervention on behalf of the client, is the other principle feature of this component. In many cases, handicapped workers will need less time spent on training and more time spent on orientation to the new work environment. Advocacy may involve a variety of different activities on the part of the job coordinator, such as: responding to a supervisor's concerns about the implications of the client's disability (likelihood of seizures, use of medication, necessity of adaptive equipment or augmentative communication systems); working out communication problems and assisting the client in developing social relationships with coworkers; or communicating with parents/caretakers about how the job is going. Although the impact of **planned advocacy** has not been evaluated in the published literature, our previous experiences have taught us that this is an essential aspect of job retention.

The following example serves to illustrate the potential impact of planned advocacy efforts. If a job coordinator notices that a client is having a difficult time locating the employee cafeteria or vending machines, interacting with coworkers during breaks, and failing to return from breaks at the appropriate time, systematic advocacy efforts should be initiated. A supervisor or coworker may be identified who will agree to asssist the client during these periods. The job coordinator may provide this "on-site advocate" with information about the client's interests and abilities, allowing the individual to more effectively communicate and interact with the client during breaks. The individual may agree to help the client obtain lunches or snacks in the employee cafeteria and may remind the client when it is time to return to the work station. The job coordinator must make certain to reward the individual for his or her efforts on behalf of the client, monitor the situation to ensure that the client continues to receive assistance as needed, and see that these activities do not place too great a burden on the supervisor or coworkers. Eliciting the aid of a supervisor or coworker is an effective method of fading the involvement of the job coordinator at the work-site and, at the same time, significantly improves the client's chances for long-term job retention.

Program Component III: Ongoing Assessment

A distinctive feature of a supported work approach involves ongoing assessment or monitoring of client performance. Typically, within more traditional job placement approaches, a rehabilitation counselor will place a client and then, at some point in the future, possibly check with employers to determine the advocacy of the client's job performance. When placing clients with severe handicaps, this type of "assessment" is often insufficient, because the worker may be terminated or quit the job before the counselor is even aware that any problem exists.

Ongoing assessment activities include the collection and analysis of subjective information obtained from employers, clients, and parents/caretakers, and the direct measurement of client behavior. Once a placement is made, there is an immediate need to gauge the employer's perceptions of the worker's performance. Initially, supervisors' evaluations should be obtained approximately every two weeks to identify any potential problems or employer dissatisfaction. When a problem is identified, this subjective information should be followed by direct measurement of the client's behavior to determine the scope of the problem and to identify potential intervention strategies. After the job coordinator has intervened to correct any problems in client performance, the results of the intervention program should be validated by again asking the supervisor to evaluate the worker. This process will ensure that improvement in the client's work performance, documented through direct measurement of behavior, is adequate from the employer's point of view.

In the same manner, the client and his or her parents/caretakers should be assessed on a regular basis to determine their satisfaction with the job placement. Identifying any concerns may allow the job coordinator to intervene before the client leaves the job. Although quantifiable data are the most desirable, in some instances verbal feedback to a job coordinator may be sufficient. In all cases, the amount of assessment data collected is clearly related to variables such as the ability level of the client, the amount of staff available for data collection, and, above all, the specific need for data to evaluate a certain problem.

Program Component IV: Job Retention and Follow-up

Follow-up, the fourth component of the model, is an activity or service consistently referred to in the rehabilitation system. However, the amount and nature of follow-up services actually provided to clients remain unclear. In a recent analysis of the Projects With Industry Program (Reismer, Haywood, & Hastings, 1983), follow-up was found to be a frequent activity of those projects. Yet, the type and quality of follow-up services and their impact on job retention were not assessed.

Systematic follow-up services are critical for a number of reasons. The client may lose enthusiasm and display a reduction in productivity after the initial excitement about the new job has subsided. A change in work schedule may require the job coordinator to retrain the client on his or her new bus schedule. Modifications in work assignment or a new supervisor may necessitate additional training on new job tasks. Similarly, a change in the home situation may adversely affect job performance and require follow-up services which involve the client's parents/caretakers. Maintaining contact with the client, employer, and parents after the initial training period will allow the job coordinator to foresee potential problems and **prevent** their occurrence, rather than delaying intervention until the problem has escalated into a crisis.

A supported work approach to competitive employment views follow-up services as long-term activities that are provided over a period of years. As indicated above, changes in supervisor, work assignment, or home situation may endanger a client's job retention years after initial placement. Traditional placement approaches that terminate follow-up services within a period of months appear unable to meet the job retention needs of severely handicpped clients, who are often adversely affected by changes in their home or work environments. Hill, Cleveland, Pendleton, and Wehman (1982) list regular on-site visits to employers, phone calls, review of supervisor evaluations, client progresss reports, and parent evaluations as effective follow-up strategies which promote job retention. Ultimately, job retention and follow-up may be the most crucial component of the supported work model, since moderately and severely handicapped workers are often immediately at risk of losing their jobs in competitive environments unless some type of retention plan is devised. Although this strategy has been viewed by skeptics as being too expensive, the benefit cost analysis of Hill and Wehman (1983) seems to refute this notion.

Implications for the Supported Work Model In Different Service Delivery Settings

Although the previous section provides important information regarding the supported work model, the model is of little value if it cannot be applied by the principle service delivery systems serving moderately and severely handicapped persons. These service delivery settings include both public schools and community service programs such as sheltered workshops and adult day programs. The section which follows specifically addresses the problems encountered in these settings and recommends changes in current policies that may help to solve these problems.

Typical Problems Encountered in Service- Delivery Settings

Public schools and community service programs each present their own unique set of problems for implementation of the supported work model. For example, relatively few university training programs equip special education or vocational education teachers with the specific competencies needed to train and place students into competitive employment, work with employers, and develop linkages with adult service systems. These difficulties have led to a minimal amount of job placement by school system personnel of handicapped students into jobs which pay **unsubsidized** wages.

Community service programs also possess many inherent problems that inhibit attempts to implement the supported work model. Funding limitations make it extremely difficult for these programs to recruit and retain qualified staff. Significant staff turnover is not uncommon. As the Bellamy, Sheenan, Horner, and Boles (1980) study noted, relatively few of the adult day programs surveyed focus extensively on vocational training and/or placement. Often community service programs are heavily influenced by volunteer groups or associations which may seek to protect handicapped adults and maintain non-vocational, developmentally-based programs.

The obstacles facing service providers attempting to implement the supported work model in public schools and community service programs are numerous and complex. Rather than dwell on these obstacles, however, it will be much more constructive to focus our attention upon ways to overcome these problems. The policy recommendations listed below begin to address some of the ways in which the supported work model can be integrated into existing service systems.

Strategies and Policies for Overcoming Public School Problems

Based upon the success of the supported work model with moderately and severely handicapped adults (Wehman, et al., 1984) it appears that this approach to job placement must be utilized fully for students who are still in public school. Such an undertaking will require extensive changes in the curriculum used with severely handicapped students, the organization of secondary programs, and the content and nature of univerisity training programs (Brown, Shiraga, Ford, VanDeventer, Nisbet, Loomis, & Sweet, in press). We have outlined below several specific policy changes which must occur to allow the application of the supported work model to the training and placement of severely handicapped students in secondary programs.

1. **Public school special education programs must make a clear philosophical commitment to place and maintain students with moderate and severe handicaps into competitive employment.** Current vocational training efforts frequently emphasize the acquisition of "prevocational" skills, evaluation activities, or training on isolated vocational tasks that bear little similarity to the skills needed for success in competitive settings. Relatively little attention is often paid to the placement of students in jobs which pay unsubsidized wages. Follow along of the students' progress is not provided. Policies must be developed at both the state and federal level that will facilitate the implementation of the supported work model. New roles must be created for vocational placement specialists to function as job placement coordinators within secondary programs for severely handicapped students. Local school systems should be encouraged to develop systematic transition programs as well as support part-time employment for severely handicapped students (Clarke, Gruenwald, Abramovitz, & Bellamy, 1980). Transition programs will enable systems to coordinate their job placement efforts with those of other agencies in their community. State education agencies can play a leadership role in developing and conducting follow-up surveys that will serve as a measure of program effectiveness.

2. **State and federal agencies must carefully monitor service delivery models, curricula, and instructional practices to facilitate implementation of all components of the supported work model.** Students confined to segregated educational facilities cannot acquire all the social and interpersonal skills required for success in competitive employment settings. Monitoring activities must guarantee students access to integrated educational environments. In addition, significant changes must occur in curriculum development activites for severely handicapped students at the intermediate as well as secondary levels. No longer can special educators be satisfied to move students through non-functional developmental sequences. Functional curricula derived through ecological inventory approaches (Welcox & Bellamy, 1982) must be incorporated through each student's intermediate and secondary programs (Wehman, 1983). The supported work model also implied a reliance upon a community-based approach to instruction. Strategies must be devised to overcome the transportation problems, liability concerns, and administrative constraints which currently hinder efforts at community-based programming (Wehman & Hill, 1982).

3. **Special education personnel preparation funds should be used to stimulate the development of university training programs that prepare specialists in the vocational training and job placement of students with moderate and severe handicaps.** Very few teachers are currently prepared at either the undergraduate or graduate levels to perform the job development, job analysis, job placement, job-site training, and follow-up activities required by the supported work model. New training programs must produce vocational placement specialists who possess the ability to work effectively with employers and personnel managers, coordinate their efforts with community service agencies, and provide quality on-site training and follow-up services.

Strategies and Policies for Overcoming Problems in Community Services

Several major policy changes and subsequent strategies need to be considered if community service programs such as sheltered workshops and adult day programs are to substantially improve their rate of job placement and retention. The suggestions which are made here are derived from policy reports, personal observations, and frequent interactions with community service personnel in many states.

1. **Public policy commitments and clear financial inducements must be established to encourage placement of people with severe handicaps into competitive employment.** Most community service programs do not have a specific mission which emphasizes the competitive employment outcomes and service provisions which purportedly lead to paid employment. Policies should be generated at both the local and State levels that prioritize client employment as a critical aspect of any program. The policies should include a clear financial inducement for competitive employment placement. As noted earlier, community service personnel receive no positive financial consequence for job placement and retention. For example, substantial cash installment payments for placement and, eight months to 10 months later, retention, would put contingencies on job placement and also job maintenance. This form of monetary contingency would greatly facilitate the use of supported work model or a very similar system. In addition, much longer follow-up period of 8-10 months must be used rather than the normal 60 days which many rehabilitation agencies tend to follow. Workers with moderate and severe handicaps require much longer periods of work adjustment.

2. **Rehabilitation agency officials who designate programs as vocational training and placement vendors for services should encourage or stimulate use of a supported work model.** In order for sheltered workshops or other community service programs to receive rehabilitation funds for client services, they must be approved as a vendor (Revell, Wehman, & Arnold, in press). During this approval process, officials should encourage the payment of monies for application of a supported work model of job placement. Similarly, rehabilitation counselors and other referring sources who are paying for workshop services must demand more in the way of competitive employment placement. When counselors become knowledgeable about the work potential of clients with severe handicaps, they may be more motivated to require specific supported work services from community service programs.

3. **More funds need to be directed to sheltered workshops and other community service programs to develop pre-employment programs closely linked to jobs in competitive employment.** A widely held assumption has been that learning general work habits and acquiring bench work skills will prepare individuals to perform competitive employment tasks in regular work settings. Our placement experiences with severely disabled clients do not support this notion. Most of these individuals need training in specific vocational skills and opportunities to learn how to interact with nonhandicapped people in community settings. The development of more work crews or sheltered enclaves in the community, as well as in-house training programs, would broaden the continuum of locally available vocational options and greatly facilitate entry into unsubsidized employment. Developmental Disabilities monies, the Joint Training Partnership Act, and local mental retardation funds may all be used to support pre-employment programs. Recently, the Social Security Act (Title XIX) Medicaid Waiver has been used in some states to successfully implement vocational training activities.

4. **Personnel in community service programs, including sheltered workshop and other rehabilitation staff, must receive extensive training in job placement, job site behavioral training, and follow-up strategies.** Federal

policymakers need to consider expending developmental disabilities, special education, and rehabilitation training funds to train community service providers. Specifically, a critical need exists for adult day program supervisors, instructors, residential counselors, case managers, respite care providers, and administrative staff who understand the importance of employment and the potential of the supported work model. In addition, significant changes should be made in university rehabilitation training programs. Preservice programs, in particular, do not sufficiently prepare personnel to effectively implement the supported work model. Much more attention must be given to active job placement, training as opposed to counseling techniques, and follow-up strategies. As clients with more severe handicaps are referred for services, counseling skills will wane in importance and behavioral training skills will become imperative.

5. **Demonstration programs need to be established for innovative community service day programs which focus on employment.** In recent years substantial numbers of special education and rehabilitation demonstration projects have validated the usefulness of the supported work model. However, few demonstration activities have been implemented in community mental retardation programs. Many more programs are needed that incorporate the most effective methods currently available for training and placing individuals with severe handicaps into jobs.

Concluding Remarks

There is a very limited likelihood that persons with moderate and severe handicaps will earn meaningful wages in real work without some approach like the one described in this paper. It is apparent to us that the type of structure and long-term commitment which is described in the supported work approach is necessary to facilitate greater opportunity for competitive employment. This paper has addressed the employment needs of the severely handicapped persons and the high rate of unemployment among disabled people in the United States today. We have recommended an approach which has worked with many moderately mentally retarded persons in the past (Wehman et al, 1982; 1984) and which requires consideration for greater accomodation into local service delivery systems. To this end, numerous public policy recommendations were made, both for public schools and also community service adult day programs and sheltered workshops. Only when more attention is paid to significantly modifying these service delivery systems to reflect employment-oriented outcomes will moderately and severely handicapped persons including those with autism, gain entry to the nation's labor force in large numbers.

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Staff Development And Training

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Staff Development and Training

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The unique patterns of strengths and deficits presented by autistic children and adults plus their differences from other groups of developmentally handicapped clients make it essential for staff working with this population to receive intensive and ongoing training. Training is essential, preferably at the university level, before entering into this field (pre-service) and must be supplemented by the ongoing development of techniques and knowledge for as long as one is working with these clients (in-service). This is especially true for those professionals working vocationally with adults because these issues present some of the most challenging questions in the field today. The present discussion will focus on the in-service training component.

General Issues

The greatest challenge confronting those developing in-service training programs is meeting the needs of personnel with a wide range of skills and knowledge. Most undergraduate and graduate training programs inadequately deal with the problems of developmentally handicapped adults and especially those with autism. On the other hand, there are some excellent training programs and also some professionals who have learned a lot through extensive, well-supervised experiences. Therefore a training program will have to be designed that will meet the wide range of trainee needs.

A second issue in designing an in-service training program is the high rate of burn-out among professionals in the field of autism. The amount of energy required to work successfully with this population plus the stress inherent in most of these jobs make the turnover rate of professionals quite high. This has two important implications for those designing in-service training programs. First, these programs must be available throughout the year so that new staff can have access to them as soon as they begin working at their jobs. Second, in-service programs not only educate but help to re-vitalize and energize staff.

Finally, any in-service training program in autism must adjust to the rapidly changing information available in this area. Autism is still one of the most poorly understood of the neurological conditions of childhood and adulthood. Each year major changes in our understanding and expansions of our knowledge are occurring at a very rapid rate. Canned and static training programs are inadequate because they will very rapidly become out of date. It is important for training programs to have access to the latest available information and to constantly update the training information in light of current developments.

Training Components

In designing an in-service training program, taking the above considerations into account, the three essential ingredients are the curriculum, availability of training sites, and the establishment of training goals. The curriculum involves the information that is disseminated to the trainees and is obviously an integral component. Any training program is only as effective as the information that is presented. We feel strongly that trainees must be able to observe the techniques and procedures that they are being trained to use. Established training sites also help keep trainers honest in that they cannot simply talk about how things should be done but rather must demonstrate the techniques as well. Any training program in the area of autism, however ambitious, will not be effective unless realistic goals are established.

Curriculum

Much has been written about curricula designed to help professionals work with autistic clients and the purpose of this brief discussion is not to rehash those issues. Obviously a firm background in developmental disabilities in general and autism in particular, curricula, training techniques, behavior management, and current trends such as independence training and community integration are essential. Discussions of curricula do not always emphasize the characteristics unique to the autistic population which require extra emphasis and skill.

Although autistic clients show many similarities to other developmentally disabled populations, there are also some unique differences which require special knowledge and skill for those working with them. Among these, a most significant one is their wide range of strengths and weaknesses. There is not another group that is so variable in their abilities and skills. Therefore, assessment techniques to fully understand these individualized patterns become much more important for professionals in the area of autism. Coordination among the people working with these clients also assumes greater importance. This makes working with parents an essential component and one that should be emphasized in these training programs as well.

Along with their unique patterns of strengths and weaknesses, autistic people generally have trouble with organizing their thoughts, in dealing with abstract concepts and generalizations. A structured approach to scheduling, presenting tasks, classroom organization, and teaching strategies is therefore imperative with these clients if they are ever to learn how to structure themselves. Trainees must be exposed to these structured teaching methods and also given an opportunity to practice them with supervision.

Finally, two of the defining characteristics of autism since Kanner's original description have been their social and communication problems. These are the most pervasive and problematic for anyone working with clients with autism. Specific, intensive training in these areas is a necessary component if one is to effectively work with this population.

Training Sites

Training sites where trainees can practice the skills they are being taught is a necessary component of TEACCH. Such sites are regular parts of the training program with experienced staff who can provide training in addition to service. For example, when training teachers, actual classrooms where trainees can do some practicum work should be provided. An ongoing vocational program is an essential component of an in-service training effort in the vocational area.

On-site training is used extensively in TEACCH in-service training efforts. Information presented in a didactic session is much more meaningful if the trainees can practice the concepts and techniques in a real vocational settting. It is also beneficial for the trainees to see the principles they have learned being modeled by experienced teachers and trainers.

The on-site training component has many benefits for trainers as well. One problem that trainers experience over time is that training activities remove them from the "real world so they do not keep abreast of current developments or realistic expectations. As a result, their training presentations can become a bit stale and unrealistic.

Although on-site training programs are generally associated with pre-service training efforts (e.g. internships), this does not have to be the case. The nature of in-service training means that experiences in these training sites will probably be limited to a week or two, but they can still be quite valuable for trainees who can learn to integrate their own experiences with what they have learned.

Training Goals

Given the enormous demands on professionals working with adolescents and adults with autism, it is impossible to provide them with all of the information, skills, and emotional suport they require. Establishing training goals or priorities is a helpful exercise to assure trainers that they are targeting the most important skills and objectives.

One of the most important goals of any training program involves the dissemination of information. Trainees must understand the unique aspects of autism if they are to perform their jobs effectively. This includes understanding ways to assess their unique strengths and weaknesses, working with families to provide continuity, and utilizing the structured teaching and educational approaches that have been the most effective with these clients. Exposure to current vocational trends and issues is another important part of the information that is disseminated.

A second major goal is for trainees to feel competent and supported. These feelings are important if the trainees are to perform their tasks effectively and remain on their jobs for any period of time. Competence is reinforced by learning information from experienced professionals and being able to practice these skills in training sites under supervision. Training classrooms also increase the trainees' feelings that they are supported because these sites give the trainees a feeling of working together with the trainers. The attitude of the trainers can help facilitate these feelings if they are positive, energetic, and interested.

Finally, an important goal of the training is to suggest that this is only the start of a process and not an end in and of itself. The continuation of the training site helps communicate this because the trainees can come back or call their trainers at any time. It is also important to have some follow-up in the trainees' own program if at all possible.

Communicating that this is only the start of a longer process is important for several reasons. First, this represents the reality in a field which is always changing and requires professionals to keep abreast of new developments if they are to remain effective. Second, it builds energy and vitality in the trainees which will help them to overcome some of the frustrations that are an inevitable part of their jobs. Finally, it makes them feel part of a larger group and effort which provides support and comfort in performing their most difficult jobs.

Conclusion

This paper has summarized some of the major issues involved with in-service training of staff working in vocational settings with autistic adults. It has highlighted important issues involved in training professionals in this area as well as the important components of any training program. Although not stated explicitly, one of the most important assumptions has been that a training program can only be effective if it is part of an ongoing program serving the needs of the clients. As a single component of such a comprehensive program, a training effort will be most effective and enduring. Without connections to ongoing service and research programs, training programs will be unable to meet the many needs they address.

Legislative, Regulatory and Financial Issues Affecting the Rehabilitation and Vocational Achievement of Persons With Autism

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Legislative, Regulatory and Financial Issues Affecting the Rehabilitation and Vocational Achievement of Persons With Autism

Frank J. Laski

Four congressional findings—standing now for nearly a decade—speak directly to the essential facts central to how persons with autism, together with other developmentally disabled persons, have been and are now treated by rehabilitation agencies and other agencies charged with the planning and delivery of vocational rehabilitation and independent living services. In its statement of purpose to the 1978 Developmentally Disabled Assistance and Bill of Rights Act the Congress found:

- individuals with disabilities occurring during their developmental period (including individuals with autism) are more vulnerable and less able to reach an independent level of existance than other handicapped individuals who generally have had a normal developmental period on which to draw during the **rehabilitation** process;
- persons with developmental disabilities (autism and other) often require specialized lifelong services to be provided by many agencies in a coordinated manner in order to meet the person's needs;
- general service agencies and agencies providing specialized services to disabled persons tend to **overlook** or **exclude** persons with autism and other developmental disabilities in their planning and delivery of services; and
- it is in the national interest to strengthen specific programs, especially programs that reduce or eliminate the need for institutional care, to meet the needs of persons with developmental disabilities.

These four findings not only describe the factual state of services for persons with autism and the desired direction of national policy, but also prescribe the necessary conditions to establish and maintain a system of rehabilitation and independent living for persons with autism. Among the necessary conditions are:

- Programs and services that are community based and are specifically structured to eliminate the need for institutional care.
- Programs and services that do not assume or require the achievement of normal developmental prerequisites for vocational rehabilitation or community living.
- Programs that take into account their past exclusion of persons with autism and as a matter of corrective justice restructure programs to effectively include them.
- Programs and services of long term duration which are properly individualized, coordinated, sequenced, managed, and followed along throughout the persons' life to insure that the right set of services provided by the right agencies at the right time to maximize the potential for independent living.

Vocational rehabilitation programs supported by the federal government and administered through state rehabilitation agencies at the present time do not fully meet these conditions. Nearly all other agencies providing adult services for individuals with severe handicapping conditions fail to address the necessary conditions. The fact that in most states no single agency is responsible for vocational and independent living services for persons with autism compounds the problem.

Today despite considerable attention to the importance of work and independent living for all, even those with most severe handicapping conditions, persons with autism are denied the opportunity to attain the dignity of productive occupation, community living and to share in the benefits of contributing to their own welfare.

Historically there are many reasons why persons with autism and other persons with severe handicaps have not been productively employed. Today, the most important reason is that they are systematically excluded from the training and rehabilitation opportunities which they need to be productive citizens. They are excluded from rehabilitation services on the basis that they have no vocational potential. Under services currently available to rehabilitation agencies, they are often considered not feasible when financial aid resources do not exist. Contrary to the judgment that persons with autism are not vocationally capable, it is now too late in the day to creditably say that exclusion of persons with autism and other developmentally disabled persons from real vocational training is because they cannot benefit from these programs. All can, when provided with the opportunity, the structure and support, do productive work. The proposition that persons with autism have little or no vocational potential is as unsupportable as the proposition that children with autism cannot benefit from education. The data are in and should by now have driven out uninformed opinions that persons with autism cannot be productively employed, and must be consigned to play at pre-work tasks in non-vocational settings. The feasibility of vocational objectives and the critical importance of productive occupation for persons with autism and other developmental disabilities is given recognition in the recent 1984 amendment to the Developmental Disabilities Act (P.L. 94-527) adding "employment-related services" as a priority service in place of "non-vocational social-developmental services."

We are all familiar with the Gold, Bellamy, Brown, **et al.** series of demonstrations of work potential of persons excluded from rehabilitation. They, however, were preceeded by a line of research dating back to at least the early sixties demonstrating successful training and placement outcomes of severely disabled persons including institutionalized persons who had been declared "non-feasible" by traditional evaluation systems used by state-federal rehabilitation agencies. [1]

Despite the continuing accumulation of data, some traditional rehabilitation agencies' practices are not unfairly characterized by the assignment of failing grades in four critical areas:

1. Failure to support and implement new training technologies which have established that severely handicapped persons can be trained to perform complex job skills in non-sheltered work environments.
2. Failure to take into account and apply evidence that evaluation as well as training must take place in real work situations and actual work environments.
3. Failure to use long-available and proven techniques from other fields (education, behavioral sciences, language) to enhance the rehabilitation potential of persons with developmental disabilities.

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[1] **See,** e.g. studies reported in Urban Institute, Report of the Comprehensive Needs Study, Washington, DC 1975, pp. 405-406.

4. Failure to sufficiently use vocational services necessary for persons with severe handicaps—particularly extended evaluation services, family services and post-employment services.

Given the persistence of these failures in the face of increasing knowledge about vocational competence of severely developmentally disabled persons and what is necessary to free that competence, it is necessary to explore the legislative, regulatory and financial barriers to rehabilitation for severely handicapped persons.

Inasmuch as the situation of persons with severe handicaps seeking access to rehabilitation services is the same as the plight of children in need of public schooling prior to P.L. 94-142[2], it is instructive to compare the federal-state legislative regulatory framework in education post-P.L. 94-142 with the existing legislative regulatory structure for rehabilitation, vocational services and independent living. By understanding those elements in P.L. 94-142 with the existing legislative-regulatory structure for rehabilitation, vocational services and independent living. By understanding those elements in P.L. 94-142 which brought an end to exclusion and promoted effective education for all children including those with autism, we may be able to specify those elements of the rehabilitation legislative structure should be maintained and strengthened, and those that must be eliminated or modified. There are five major legislative principles that undergird and direct the right to eduation, which I believe must be accepted and incorporated in post-school services and particularly vocational rehabilitation services. They are:

1. **Zero reject** - Access to free public education must be provided for all children and youth regardless of degree of exceptionality or fiscal impact on the school system.
2. **Integration** - Education should be provided in the most integrated, normal setting possible that is consistent with the learning needs of the individual. A presumption is made against segregation and in favor of the most integrated, least restrictive environment possible.
3. **Appropriateness** - Education must be based on an individualized program that is appropriate to the needs of the child.
4. **Due process** - Opportunity must be made available for a notice or a hearing appeal with respect to placement or other changes in educational programs.
5. **State of the Art Requirements** - implicating both teacher training and effective training methods and giving meaning and context to "appropriate education."

In practice many of the above principles are not followed by rehabilitation and independent living programs as applied to persons with autism. However, all are present in the legislative and regulatory scheme. In the Rehabilitation Act and its implementing regulations the appropriateness, individualizing and due process principles are equivalent if not stronger than their P.L. 94-142 counterparts. In fact, in one of the few judicial interpretations of the program provision of the Rehabilitation Act, the federal district court noted, "One of the paramount goals of the Act is to provide rehabilitation services which are tailored to each individual's needs. ..." **Scott v. Parham**, 422 F. Supp. 111, 113 (1976). The importance of the individualizing and due process provision are further elaborated below after a discussion of those principles that are not sufficiently in place: zero reject, integration and state of the art.

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[2] Compare pre P.L. 94-142 school officials' explanations to parents for exclusion of severely handicapped children: e.g., "We do not have classes for autistic children."; "we do not accept handicapped children who have behavior problems;" or "we are going to excuse your child because she **can no longer benefit** from our program." (Lippman & Goldberg, 1973).

Zero Reject

Without a doubt the most important aspect of the right to education movement codified in P.L. 94-142 was the zero reject principle. The requirement of access to all children regardless of severity of handicap put an end to the notions of behavioral pre-requisites for schooling and ability to benefit from schooling and rendered irrelevant as an initial matter the school's negative expectations and programmatic inadequacies. The principles of zero exclusion forcing the local and state educational authorities to accept the responsibility for **all** cannot be underestimated as the driving force to the decade of positive developments toward effective education for severely handicapped children. It is common to contrast education and rehabilitation in terms of access. Education, it is said, is an entitlement. Rehabilitation, on the other hand, is a discretionary system, selection if not sorting, is allowed and expected. Limited funds per force limit access, clients and services. These distinctions are too simplistic to determine the real differences in access to services. We must examine closely the eligibility and order of selection provisions in the Rehabilitation Act and its implementing regulations.

Under the Rehabilitation Act only two eligibility criteria must be met:

- The presence of physical or mental disability which for the individual constitutes or results in a substantial handicap to employment; and
- Reasonable expectation that the provision of vocational rehabilitation services can benefit the individual in terms of employability.

The federal regulations define further the key eligibility criteria. "Physical or mental disability" means "a physical or mental condition which materially limits, contributes to limiting, or if not corrected will probably result in limiting an individuals' activities or functioning."

"Substantial handicap to employment" means "that a physical or mental disability...impedes an individual's occupational performance by preventing his obtaining, retaining or preparing for employment consistent with his capabilities and abilities."

All applications for services and referrals must be handled to insure that each disabled person receives a speedy and fair determination of eligibility. The first step in the process is the preliminary diagnostic study to establish the existence of physical or mental disability, extent of employment handicap, and whether vocational rehabilitation services will benefit the individual in terms of employability. There are three possible results of the preliminary diagnostic study.

1. **Disabled person found eligible** - Then the counselor must prepare and sign a certificate of eligibility and the client will proceed to further evaluation and services.
2. **Disabled person found ineligible** - Then the counselor must prepare and sign a certificate of ineligibility determination and inform the person of the right to challenge the decision, and have an administrative review and fair hearing. The ineligibility certification, like all other decisions in the rehabilitation process, must be made only "after full consultation with the individual or as appropriate his or her parent, guardian or other representative."
3. **Disabled person needs further evaluation to determine eligibility** - In most cases for persons disabled by autism and other severely handicapped persons, it will not be possible to determine vocational potential on the basis of a preliminary

diagnostic study or a short term evaluation. In those cases the law and regulations provide for a period of "extended evaluation" which can last for up to eighteen (18) months. Therefore, rather than a yes or no on eligibility for services, the person is found eligible for extended evaluation and the counselor signs a certificate of eligibility for extended evaluation. During extended evaluation the client is entitled to a wide array of services to determine vocational potential and has all the rights of a rehabilitation client.

The legal provisions for extended evaluation are among the most important protections in the law for persons with autism and others whose work potential is not obvious. Their proper application allows for a wide range of vocational services to be provided over an extended period of time in real work settings, structured and supported by staff trained in designing and implementing teaching strategies for persons disabled by autism. Given what we know about the complexity of assessing vocational potential of persons with autism and the uselessness of traditional modes of short term evaluations in sheltered work settings, it is reasonable and sound to recommend that no person disabled by autism be declared ineligible for vocational rehabilitation services on the basis of a preliminary diagnosis that concludes the individual has no vocational potential. In every case the eligibility determination should be made only after extended evaluation in a properly staffed, supervised and structured non-sheltered environment.

The eligibility process contemplated by the law and regulations is fairly simple, however in practice it has presented serious problems to applicants who are severely handicapped. Persons disabled by autism should never have a problem meeting eligibility criteria related to the existence of disability or substantial handicap to employment. (see discussion of definitions, **infra**). However, the criteria of "employability" is often used to exclude severely handicapped individuals.

Since the application of the "employability" is essentially a prediction (the law says "an expectation") about an individual's vocational potential, it is important to understand the process for making the determination (who makes it, how, how valid it is, who can challenge it, what happens if no prediction can be made at the time of application). Determinations based on traditional assessment tools (e.g., IQ tests, aptitude tests, adaptive behavior checklists, work samples) in traditional settings (workshops for persons with retardation, comprehensive rehabilitation facilities) should be challenged inasmuch as rehabilitation agencies are likely to use these and other assessment procedures originally developed for less handicapped individuals and apply them invalidly to persons disabled by autism.

Special scrutiny must be given to agency decisions finding a disabled person ineligible because the individual is "not feasible" for rehabilitation or not capable of "competitive employment" or "gainful employment." These statements reflect the tradition of vocational rehabilitation agencies to focus on and overemphasize "gainful employment"; however, in 1973 the emphasis was shifted to "employability," and priority was placed on severely handicapped persons who require multiple services over a long period of time to achieve their vocational potential. Still, many counselors and supervisors have not adjusted their practices to conform to the letter and spirit of the Congressional reforms.

Rehabilitation agencies, like many other agencies serving disabled people, have a greater demand for services than they can supply. At various times, shortage of staff, lack of funds, and shortage of providers make it impossible to serve all clients. To deal with this problem, Congress requires state rehabilitation agencies to set forth in writing the order to be followed in selecting groups of handicapped individuals to be provided to all eligible individuals. This "order of selection" must assure that those groups of individuals with the most severe handicaps are selected for service before any other group of handicapped individuals. Therefore, under the law, severely handicapped individuals have more than equal access to rehabilitation services; they have a priority. They must be served first.

Persons with autism should fall under the definition of severely handicapped and be entitled to priority consideration from the agency.

A reading of the current definitions of "severely handicapped individual" may raise doubts as to the inclusion of persons disabled by autism. Although persons with autism clearly meet the functional limitation and service criteria[3] in the definition, autism is not enumerated in the laundry list of twenty-six disabling conditions. Therefore, it is arguable that a person with autism, must on a case by case basis be determined to have a disability which causes "comparable substantial functional limitation" to the disabilities listed. Such a case by case evaluative approach to classify persons as severely handicapped, may serve a few persons disabled by autism, but it does not serve a federal policy designed to give priority to severely handicapped, and it effectively excludes persons with autism from the order of selection policy. Given the lack of specification of autism, no state can be expected to include persons with autism in their state plans for order of selection. The specification of autism would also facilitate the collection of data concerning services to persons with autism and focusing the attention of state agencies on the population. It is therefore recommended that the federal regulations specifying conditions which result in severe handicap be amended to include autism.

If persons with autism were specifically designated as severely handicapped setting them up for priority consideration for services and appropriate evaluation settings, and services were used during an extended evaluation period (given adequate resources), rehabilitation would move closer to the zero reject system familiar in education. However, considering the current resources of state rehabilitation agencies it is unlikely that without more changes the functional equivalent of zero reject will be created.

Individualized Planning and Due-Process

Once persons with autism gain access to rehabilitation agencies, securing a fair share of appropriate rehabilitation services requires activating the individualized planning and due process requirements prescribed by the Congress in 1973. The Individual Written Rehabilitation Program (IWRP) is central to receiving full service entitlement under the Rehabilitation Act; it operationalizes the federal individualizing and appropriateness mandates. As the court noted in **Scott v. Parham**, the IWRP provision

> "was added to the Act because: 'It became apparent that the individual client was not being sufficiently consulted on his own behalf in tailoring the rehabilitation program to his individual needs." [4]

Those familiar with the Individual Education Plans (IEPs) required to guide education will recognize much similarity in the practices and procedures relating to the IWRP.

IWRP Content Requirements

The federal law and regulations specify what must be contained in the IWRP. It must include:

- The basis for eligibility determination
- Statement of intermediate rehabilitation objectives to attain long range goals

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[3] i.e., a handicapped individual (1) who has a severe physical or mental disability which seriously limits his functional capacities (mobility, communication, self-care, self-direction, work tolerance, or work skills) in terms of employability; and (2) whose vocational rehabilitation can be expected to require multiple vocational rehabilitation services over an extended period of time.

[4] 422 F. Supp. 111, 113 (1976) (citations omitted).

- Date of the start of each service
- Statement of how long each service will be provided
- Procedure and schedule for reviewing the progress of the rehabilitation plan
- Statement of how long each service will be provided
- Procedure and schedule for reviewing the progress of the rehabilitation plan
- Statement of the views of the individual or the client's advocate concerning the goals and objectives set
- Statement of client responsibilities including any financial responsibility for cost of program
- The basis for determination that the client is "rehabilitated"
- Statement of plans for post employment services
- Statement that the client has been informed of the right to challenge agency decisions and the right to seek administrative review and fair hearing
- Statement of all the terms, conditions, rights, remedies under which goods and services will be provided.

IWRP - Procedural Requirements

The procedure to be followed in developing the IWRP is just as important as what is in it. In fact the procedure will in many cases determine what ends up in the IWRP and determine how useful it will be to the client. Four simple requirements must be followed:

1. The IWRP must be in writing.
2. The IWRP must be developed jointly in full consultation with the client or, as appropriate, a parent, guardian or representative.
3. The counselor must provide a copy of the IWRP to the client or, as appropriate, a parent, guardian or representative.
4. The IWRP must be reviewed periodically (at least once a year) jointly by the counselor and client.

After the IWRP is written and agreed to by the counselor and client, the law and regulations set forth additional procedures which must be followed if services are to be terminated because the disabled person is not capable of achieving a vocational goal.

A client cannot lawfully be terminated from vocational rehabilitation services (or extended evaluation services) unless:

- The agency makes a decision that the client has no vocational potential.
- The agency makes the decision in full consultation and participation with the client or his representative and records the view of the client in the IWRP.
- The reasons for the decision are recorded in the IWRP.
- There is a periodic review (at least once a year) of the termination in full consultation with the client.

These requirements make it clear there is a strong presumption in favor of continuing disabled persons in rehabilitation programs. The disabled person is to be given every benefit of the doubt. Only when it is clear that the person cannot meet a vocational goal is termination justified.

Despite its extensive substantive and procedural requirements, the IWRP has not been fully utilized to effect the configuration of services provided by vocational rehabilitation agencies. Too often, routinized sets of diagnostic, evaluative, counseling, and training services nearly always related to sheltered work settings and sheltered work outcomes are provided. Services are likely not to be determined on the basis of individual need if preordained contractual arrangements between state agencies and rehabilitation facilities and sheltered workshops exist. Despite the limitations of rehabilitation services and the non-availability of services appropriate to persons with autism, under the federal law there is a broad scope of rehabilitation services available to persons with disabilities, and vocational rehabilitation services can include virtually any goods or services that can be used to assist disabled persons in terms of their employability. [5]

The listing of services in the Rehabilitation Act and the federal regulations clearly shows that the rehabilitation program is potentially equipped to provide a great range of services to assist disabled people to prepare for and enter the work force. Of course, no client will require or receive all services. The rehabilitation counselor, working and consulting with the client, has the job of putting the services together in individual plans to enable disabled persons to reach their maximum potential.

In terms of its legislative and regulatory base, one of the greatest strengths of the rehabilitation program is the broad scope of services that can be provided and the flexibility rehabilitation officials have to arrange services in an individual program plan to meet the person's needs. It is also possible for state agencies to provide for services "which may be expected to contribute substantially to the rehabilitation of a group of individuals but which are not related directly to the individualized rehabilitation program of any one handicapped individual." Thus it is possible for an agency either on an individual or group basis to design and support programs and services which include the key program elements necessary for persons with autism to achieve vocational goals (e.g. highly structured programming; staff trained in behavioral sciences; frequent individual staff attention in teaching new tasks; support from interdisciplinary teaching team). To make this possibility real does not necessarily require new authority but rather regulatory and fiscal incentives to focus state attention and reallocate resources away from nonfunctional sheltered work programs to nonsheltered supported work programs.

There are two legislative-regulatory engines that have driven federally funded education programs that have not been applied to vocational or other adult programs serving severely handicapped persons. These are the integration requirement and the state of the art requirement.

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[5] (1) Diagnostic and evaluation services; (2) counseling and guidance services; (3) physical or mental retardation services; (4) training; (5) income maintenance; (6) transportation; (7) family services; (8) interpreter services for deaf individuals; (9) reader services; (10) telecommunications; (11) placement; (12) Post employment services; (13) other goods and services which can reasonably be expected to benefit a handicapped individual in terms of employability.

Integration

While the Rehabilitation Act in its general purposes and in its recent expansion to include independent living is consistent with the integration thrust of the Education Acts and the DD Act, unlike those acts [•] nowhere is the integration imperative operationalized at the federal or state level. In fact the federal-state rehabilitation program is neutral as to whether its programs and services are provided in segregated or integrated settings. In some states a rehabilitation success is counted as a success whether it is in an integrated work station or a subminimum wage-work activity center. Rehabilitation outcomes for developmentally disabled persons are often in non-productive segregated settings. It has long been clear that separate environments are not only unnecessary, but actually destructive, in the education of severely disabled children. They are useful, if at all, only for a tiny number of children and then only for sharply limited periods. Classes for children with severe disabilities may sometimes be self-contained, but in schools where ordinary children attend, interaction occurs and integrated community settings are part of the teaching.

Just as in schooling, it is arguable that integration is a substantive component of effectiveness of vocational services for severely handicapped persons. It is certainly a necessary element of a post-school program where the child's education has been integrated, functional and community based. The reasoning of Judge Vance, as to integration of a severely handicapped teenager applies just as well to vocational programming. Ordering an integrated school program, the Judge found

> "Joseph is not placed into contact with non-handicapped children to the maximum extent consistent with an appropriate education program. Although defendants' experts dispute the soundness of the main-streaming approach to the education of the handicapped, Congress has made a clear choice among the competing educational philosophies....No evidence suggested that Joseph would be unable to benefit from increased contacts with non-handicapped students provided he receives proper supervision. On the contrary considerable evidence established that such interaction is essential to provide him with role models and to increase his ability to act independently."

State of the Art

While the Rehabilitation Act has decent individualizing and due process requirements, experience proves that such one-by-one administrative mechanisms are effective in securing a proper result where a decision is posed among alternative services or programs which already exist. They are not to be relied on to create new arrangements of services such as those needed by persons with autism. For that, executive incentives and enforcement will be necessary. One of the planning and administrative tools that can be used by the executive (and sometimes by the courts) is the requirement of personnel development and training to

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[•] The integration imperative in P.L. 94-142 is §1412(5) (B) requiring states establish procedures to insure

> "that to the maximum extent appropriate, handicapped children, including those children in public or private institutions or other care facilities, are educated with children who are not handicapped, and that special classes, separate schooling, or other removal of handicapped children from the regular educational environment occurs only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."

For cases interpreting the meaning of the integration imperative, **see New York State Association for Retarded Children v. Carev, Roncker v. Walter, Campbell v. Talladega County Board of Education,** and **PARC II.**

master state-of-the-art techniques. That tool is available for enforcement in states and at the federal level in matters related to state-of-the-art requirements for educators of handicapped children by virtue of §1413(a)(3) of P.L. 94-142. When it created the right to education, Congress knew in directing that all handicapped children be educated, that it was possible. Congress knew that it was known how to educate disabled children effectively, particularly those most severely disabled. Congress knew also that the knowledge of how to do so was not widely distributed.

The Congress therefore, imposed two duties in every local and state education authority:

> "(A) the development and implementation of a comprehensive system of personnel development which shall include the inservice training of **general** and **special** educational **instructional and support personnel,** detailed procedures to assure that all personnel necessary to carry out the purposes of this chapter are appropriately and adequately trained, and effective procedures for **acquiring** and **disseminating** to teachers and administrators of programs for handicapped children **significant information derived from educational research, demonstration,** and **similar projects,** and
> "(B) **adopting,** where appropriate, **promising educational** practices and materials."

Section 1413(a)(3), cited by Supreme Court Justice Rehnquist as a "clear statutory directive" establishes a duty to adopt "promising practices" and a duty to train personnel to master state of the art. However, comparable provisions, thus comparable leverage, does not seem to exist in the Rehabilitation Act and regulations to be sure training authorization is there "to increase the level of skills" of rehabilitation personnel.

A state-of-the-art training requirement and a state plan requirement for a comprehensive system of personnel development, not for rehabilitation generally but targeted on creating new programs and resources for heretofore unserved severely handicapped individuals, would make sense for persons with autism and equipping state agencies to serve persons with autism.

A Note on Financial Barriers

There is an increasing awareness that federal-state funding patterns feeding services and programs for the severely handicapped do not support and in fact are counter-productive to the stated national purpose of achieving for all persons with disability an integrated, normalized life—full of opportunity for productivity and independence. [7] Using the developmentally disabled as a base, federal expenditures are skewed toward custodial services for a small part of the population resident in large institutions. Health Care Finance Administration programs, which by administrative fiat are contrary to congressional attention, exclude expenditures for education and training comprise 56% of all federal DD costs. Department of Education DD expenditures by contrast represent 4% of all federal costs. [8] Similarly, day activity programs supported by a growing patchwork of state and federal funds typically provide congregate care in segregated settings at an annual cost of about $4,000 per client.

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[7] That purpose was best stated by the Congress in P.L. 93-516 in its finding that,

> "It is essential...that all individuals with handicaps are able to live their lives independently and with dignity, and that the complete integration of all individuals with handicaps into normal community living, working and service patterns be held as the final objective(.)"

[8] These figures are from HHS, Office of Inspector General, A 'Program Inspection on Transition of Developmentally Disabled Young Adults from School to Adult Services', 11/14/53.

The rapid growth of federal expenditures for institutional care ($602 million in 1976 to $3.6 billion in 1984) led the Congress to provide some relief for community programs by enacting the Medicaid Waiver provisions of the Omnibus Reconciliation Act of 1981. Those provisions give states the option of providing alternative home and community based services to persons in ICF/MR facilities. While the waiver provisions held significant potential for moving state support from institutions to community services, the administration of the waiver has created new obstacles to the creation and maintenance of vocational services for severely handicapped individuals. Prohibition of vocational training and employment as legitimate habilitation services under medicaid has simply moved states to create additional non-productive day programs.

While the Congress has been clear in Medicaid law as well as its other enactments, as to its commitment to habilitative services that lead to independence and employment, it supports and fosters dependency and segregation.

The extent of the discrepancy between our stated national values and our financial arrangement requires serious address and reform by the Congress and the Administration. The current vehicle for reform is the "Community and Family Amendments Act of 1984." That bill, the successor to Senator Chafee's S.2053 would in an orderly and planful way work a redirection and reallocation of federal and state funds to serve the national interest in a fully integrated community life for persons with severe handicaps. Its enactment and proper implementation would provide a chance for persons with autism and other severe handicaps to live as independently as possible, work and contribute to the life of the community as they are able, and achieve the dignity that comes from doing so.

Small Group Reports and Recommendations

Group I

Recommendations Regarding Legislative, Regulatory and Financial Issues Related to the Provision of Vocational Rehabilitation Services to Persons with Autism

Committee Members

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Statement of Status and Barriers to Assessing Vocational Rehabilitation Services for Persons with Autism

The Committee accepted the paper prepared by Frank Laski regarding status and barriers to the vocational rehabilitation system by people with autism. The paper should be read in its entirety to fully understand the problems faced by people with autism in their efforts to assess the system. The following is a synopsis of the paper with quotations as deemed beneficial to the reader with reference to the appropriate page in the full document provided for easy reference. While it is hoped that every reader of this monograph will read the entire paper, it was felt that the most salient point should be addressed in this presentation of recommended goals, objectives and strategies based upon the paper.

As noted in the paper, people with autism are less likely to reach independence than people who are in need of rehabilitation but who had a normal developmental period. They often require lifelong services coordinated among many sources and they have been overlooked within the system. The committee believes it is in the best interest of the nation to strengthen services which will increase the independence of people with autism and decrease the need for institutionalization.

Conditions cited as necessary for rehabilitation and independent living for people with autism as defined by Laski included:

1. Programs and services that do not assume or require the achievement of normal developmental prerequisities for vocational rehabilitation or community living.
2. Programs that take into account the past exclusion of persons with autism and restructure programs to effectively include them.
3. Programs and services that are community based and are specifically structured to eliminate the need for institutional care.

4. Programs and services of long term duration which are properly individualized, coordinated, sequenced, managed, and followed along throughout the persons' life to insure that the right set of services is provided by the right agencies at the right time to maximize the potential for independent living.

These are prerequisites to development of work and independent living situations, but are not part of the vocational rehabilitation program. The lack of a single entity responsible for development of these services is one major problem factor. Another major barrier has been the exclusion from rehabilitation services of persons with autism. This is based either upon lingering misconceptions that persons with autism have little potential to work or that resources necessary to effect job placement are currently unavailable through many rehabilitation programs. As the conference so readily showed, "Contrary to the judgment that persons with autism are not vocationally capable, it is now too late in the day to creditably say that exclusion of persons with autism and other developmentally disabled persons from real vocational training is because they cannot benefit from these programs." In addition, "The data are in and should by now have driven out uninformed opinions that persons with autism cannot be productively employed, and must be consigned to play at pre-work tasks in non-vocational settings." As the CSAAC experience so credibly showed conference participants, persons with autism can live and work in the community when provided with the necessary support.

Laski compared the legislative and regulatory structure for rehabilitation, vocational services and independent living to that of P.L. 94-142, the Right to Education for all Handicapped Children Act and identified the five following concepts which promoted the end to exclusion of people with autism (and other disabilities) from the education system and provided the following recommendations:

1. **Zero Reject**

   This principle requiring education for **all** was instrumental to development of appropriate educational programs for severely handicapped children. While education is considered an entitlement, rehabilitation is a discretionary system where determination of eligibility based on the existence of a physical or mental disability, the extent of the employment handicap and determination of whether vocational rehabilitation services will benefit the individuals employability, makes the provision for use of extended evaluations one of the most important protections provided in the law for persons with autism. Laski states that "Given what we know about the complexity of assessing vocational potential of persons with autism and the uselessness of traditional modes of short term evaluations in sheltered work settings, it is reasonable and sound to recommend that no person disabled by autism be declared ineligible for vocational rehabilitation on the basis of a preliminary diagnosis that concludes the individual has no vocational potential. In every case, the eligibility determination should be made only after extended evaluation in a properly staffed, supervised and structured nonsheltered environment."

   Also important to people with autism is the Congressional requirement that state rehabilitation agencies set forth in writing their "order of selection" to assure that the most severely handicapped are selected for service before any other group of handicapped individuals. While people with autism meet the functional limitation and service criteria for severely handicapped, they are not included in the federal laundry list of twenty-six disabling conditions, leaving determination to be considered on a case by case basis. Since autism is not specified as a severely disabling condition at the federal level, no state can be expected to include autism in their state plans for order of selection.

2. Individualized Planning

The Individual Written Rehabilitation Program (IWRP), simillar to the Individualized Education Plan, (IEP), is central to the rehabilitation process and provides the means for recieving full service entitlement under the Rehabilitation Act. While the provision is meant to ensure that any necessary goods or services be used to assist persons to be employable, people with autism will need to be sure that routine diagnostic, evaluation, counseling and training services not become the norm. The legislative and regulatory bases of the rehabilitation program provides for a broad array of services and flexibility in meeting individual needs, and regulatory and fiscal incentives need to "...focus state attention and reallocate resources away from nonfunctional sheltered work programs to nonsheltered supported work programs."

3. Due Process

Strong procedures for due process are incorporated in the Rehabilitation Act for development of the IWRP. Procedures for development of the IWRP include that it be in writing, that it be developed jointly with the client, or as appropriate, a parent, guardian or representative, that a copy be provided to the client or other as specified above and that it be reviewed periodically (at least once a year) jointly by the counselor and client. Following development of the IWRP, procedures in the Act provide a strong presumption in favor of continuing the person in the rehabilitation program. Despite these procedural requirements, needed services have not been provided since routine services have been provided during the devlopment of the IWRP and Rehabilitation personnel and clients will need to be creative in development of the IWRP in order to ensure appropriate services.

4. Integration

This concept from P.L. 94-142 of integrating the disabled into the mainstream has not been included in the Rehabilitation Act which is neutral on the subject of where services should be provided. Laski points out that segregated settings for educational services have been shown to be destructive, and when useful, are so if only for a short time for a small number of individuals. While he says that just as it is arguable in schooling that integration is a substantive component of effectiveness of vocational services for severely handicpped persons, "It is certainly a necessary element of a post-school program where the child's education has been integrated, functional and community based."

5. State of the Art

In creating P.L. 94-142, Congress knew that disabled children could be effectively educated, but they also recognized that the knowledge of how to do this was not widely distributed, and therefore included provisions for develoment of a comprehensive system of personnel develoment and the adoption where appropriate of promising educational practices and materials. Comparable provisions do not exist in the Rehabilitation Act and "A state-of-the-art training requirement and a state plan requirement for a comprehensive system of personnel develoment, not for rehabilitation generally but targeted on creating new programs and resources for heretofore unserved severely handicapped individuals, would make a major contribution to breaking down barriers to development of program models that make sense for persons with autism and equipping state agencies to serve persons with autism."

In discussing financial resources for rehabilitation and independent living and barriers to the development of these services, Laski noted that there is an increasing awareness that federal and state funding patterns do not support the "...stated national purpose of achieving for all persons with disability an integrated, normalized life—full of opportunity for productivity and independence"(a purpose best stated by Congress in P.L. 93-516). While the growing federal expenditure for institutional care led Congress to enact Medicaid Waiver provisions to provide states with the option of providing alternative home and community based services, the prohibition of vocational training and employment as a legitimate habilitation service under medicaid has caused states to create additional non-productive day programs. Laski says that the Community and Family Living Amendments of 1985, "...would in an orderly and planful way work a redirection and reallocation of federal and state funds to serve the national interests in a fully integrated community life for persons with severe handicaps. Its enactment and proper implementation would provide a chance for persons with autism and other severe handicaps to live as independently as possible, work and contribute to the life of the community as they are able and achieve the dignity that comes from doing so."

With this statement of the status of people with autism in regard to the vocational rehabilitation system and the barriers they face to accessing the system, the committee developed the following goal, objectives, and strategies for the achievement of their goal.

Goal: To assure that people with autism are served by the Vocational Rehabilitation system so that they may obtain and maintain non-segregated, paid employment in the business and industry of the community.

Objectives:

1. To cause necessary changes in the Vocational Rehabilitation regulations and guidelines (VR Handbook) which will make the system more accessible to people with autism.

Strategy for Achieving this Objective:

To ask the Secretary of Education to designate autism as a severely handicapping condition under the authority in Section 29 USC 706 (12). The National Society for Children and Adults with Autism (NSAC) will initiate this action by letter to the Secretary. Follow-up action as necessary will be taken, including as appropriate, involving chapters in the effort of educating the Secretary as to the importance of this action.

2. To assure that code 526 (Autism) in the VR manual is used in each state to record the number of persons with autism admitted into the system and successfully placed.

Strategies for Achieving this Objective:

a. NSAC will develop an information packet on the Rehabilitation system and the importance of the use of Code 526 for chapters to use as background information for contacting their state rehabilitation office. Chapters will be asked to contact the state agency to determine whether and how the code is being usd in their state and will report their findings to NSAC.

b. NSAC representatives and the Virginia VR Director will meet with the Client Services committee of the Council of State Aministrators of Vocational Rehabilitation at their Spring, 1985, meeting to report on the results of this national conference and request them to survey the states to establish the extent of services provided to people with autism and to take action as necessary within their states to ensure the appropriate use of the 526 code.

3. To request establishment of a national steering committee to oversee the development and implementation of the recommendations of this conference to ensure that appropriate methods for training vocational rehabilitation personnel to work with people with autism are developed and implemented as an outcome of these proceedings.

Strategies:

a. Copies of the proceedings of the conference will be made available by NSAC to members of the congressional committee which requested this study be performed with information on the importance of follow-up activities to achieve the stated goal.

b. Members of the steering committee for the national conference will meet with the Assistant Secretary for Education and Rehabilitation to report on the outcomes of the national conference and seek assistance as appropriate.

4. To establish a cooperative agreement between CSAVR and NSAC for provision of nonsheltered, integrated, paid employment of people with autism; and the establishment of systems which will provide persons with autism access to vocational rehabilitation services.

   Strategies:

   a. NSAC will write the President of CSAVR to report the results of this conference and to officially propose a cooperative agreement.

   b. The Steering Committee will consider the recommendations of this conference and prepare a draft cooperative agreement for approval by the full Board of Directors of NSAC and the CSAVR. Discussions between CSAVR and NSAC will take place as necessary in the development of the statement of cooperative agreement.

   c. Following approval of the draft agreement by the Steering Committee and NSAC, members of CVSAR serving on the Steering Committee will present the agreement to CSAVR for approval.

5. To develop an orientation training package on autism for VR counselors, VR supervisors and others so that training can be conducted in all states.

   Strategies:

   a. A subcommittee of the National Steering Committee will meet with NIHR to discuss the feasibility of funding a National Research and Training Center initiative to establish a national training package to be made available to those identified above, including the development of a national training team which will be available to provide the training.

6. To develop appropriate vocational evaluation mechanisms as tools for assessment to be used for determining means of providing nonsheltered, integrated paid employment.

   Strategies

   a. Request the Assistant Secretary of Special Education and Rehabilitation to fund demonstration projects for serving persons with autism and similiar severe communication and behavior problems in integrated community settings.

b. Request the Assistant Secretary of Special Education and Rehabilitation to establish a Rehabilitation and Training Center in autism and other severe communication and behavior disorders through an RFP to be developed and funded by 1987.

7. Educate policy makers on the need to eliminate prohibitions on vocational training and employment-related services in medicaid funded programs.

Strategies:

a. Brief relevant Health and Human Services officials and members of Congress on the negative impact of this prohibition on persons with autism.

b. Brief relevant Congressional officials on the relevance of the Community and Family Living Amendments in alleviating problems in this area.

8. To educate policy makers on means to enable people with autism to retain health benefits under medicaid while engaged in competitive employment and/or supported nonsheltered work.

Strategies:

a. The Steering Committee will determine the progress being made by the Department of Education and other federal agencies in the dissemination of information regarding retaining benefits while engaged in nonsheltered, community employment and will formulate specific strategies to encourage this Congressionally mandated activity. These strategies will include activities to encourage and enable client-assistance projects in the 50 states to disseminate information to clients, parents, advocates, service providers on how workers with autism and other disabilities can maximize SSI and health benefits while engaged in nonsheltered community based employment.

Group II

Nonsheltered Employment Models Committee

Committee Members

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I. Statement of Status

The committee could identify only a few isolated examples where adults disabled by autism were benefiting from nonshelterd employment and training opportunities. Examples included supported employment and training at Community Services for Autistic Adults and Children, Rockville, Maryland, where 37 adults are currently employed in 17 different companies and receive instruction and monitoring by CSAAC paid counselors; A program serving one individual in West Virginia who works part-time in the library and is supervised on a one-to-one basis; an adult in North Carolina who is supported in training and on-job supervision by a counselor paid by D.V.R.

The committee agreed that supported and other nonsheltered employment programs need to be studied nationwide. All agreed that nonsheltered employment is possible for all adults disabled by autism, regardless of the severity of their disability or behavioral disorders. The committee noted that many supported employment programs serving mentally retarded individuals exclude persons with severe disorders of behavior. The committee identified three existing basic models of nonsheltered employment programs:

A. Evaluation, Training, and Placement Model

This model is the typical "**DVR** Services Model." The client is evaluated by standardized measures; career and job training is provided, typically in a workshop or school setting; after successful completion of training the adult is placed on a job. If instruction or training is provided on the job, it is time-limited.

B. Enclaves in Industry Model

Monitored supportive employment with four or more disabled adults working as a team in industry.

C. Supportive - Monitored Employment Model

(C-1) (CSAAC Model)

Vocational assessments are conducted in nonsheltered sites; program plans and placements are developed based on individual strengths and needs; training supervision and professional, related services are provided for the individual paid by the providing agency for as long as the individual requires these supports to maintain employment.

(C-2)

Provider agency trains employee of the employer to be a monitor of the disabled individual. The monitor is paid by the employer.

(C-3)

Provider agency trains employee of the employer to be a monitor of the disabled individual and pays an additional stipend to the monitor.

(C-4)

Provider agency pays the company to pay the disabled adult to train and work in a nonsheltered company.

II. Employment and Training Barriers for Persons Disabled by Autism to Enter Existing Models

Overall Barriers

Persons disabled by autism have been among the last to receive integrated public education and to exit the institutions. In 1977 a study revealed that over 95% of all adults disabled by autism were eventually institutionalized. Programs serving other disability populations frequently do not have staff trained to implement services with persons disabled by autism. Criteria for admission or remaining in a program often exclude persons who exhibit certain behaviors which may either be related to the disability of autism or the mismanagement of the client by teachers or other direct care workers lacking knowledge, training or skills in service delivery of this population.

We have seen examples, i.e. Wisconsin, where school-aged children can be integrated into public school programs with regular students and in special programs with students with other disabilities. We also know that adults with this disability can live and work among their non-handicapped peers in nonsheltered worksites and in community living arrangements, i.e. CSAAC program.

The following barriers were discussed in reviewing each of the identified nonsheltered employment models:

A. RSA Model

Existing evaluation techniques used by most RSA programs are inadequate to determine eligibility and vocational programming for most people with autism; many programs do not provide sufficient support to meet employment needs for persons disabled by autism; RSA agencies do not have the resources to employ efficient staff to some persons with autism.

B. Enclave Model

The **enclave model** is not appropriate for persons disabled by autism since interactions and integration with other non-handicapped individuals is critical for job adjustment and role models. This model, where four or more persons disabled by autism or other developmental disabilities work as a team, is not acceptable because of difficulty in managing difficult behaviors which is a criticl issue for successful employment for this population.

C. Supported Employment Models

(C-1) The current supported employment models lack funding needed for adequately trained personnel; there is need for public education to overcome the assumption that persons with autism cannot work.

(C-2) The model by which the agency trains an employer may hinder entry into the workplace since it relies on employers' resources. The model may be used as an adjunct in fading provider-agency monitor as a component of C-1 model.

(C-3) This model may be problemmatic if company requires productivity rates for employees. There may also be a problem with employee having two supervisors and other management problems if monitor does not perform in either of the jobs.

(C-4) This model does not encourage commitment and discourages desired attitude of disabled adult as a valued employee. The committee views this model as being a barrier to full paid employment and attitudinal change.

III. Preferred Model

The unique characteristics and needs of persons with autism strongly indicate that the supported employment models are the preferred mode of diagnosis, training, and placement.

IV. Strategies for Eliminating Barriers

A. RSA Model

Autism must be listed as one of the severely handicapping conditions and targeted as a priority population for services to be developed. VR staff requires training to appropriately serve persons disabled by autism. Training and other services provided by VR staff of contracted by VR agencies must reflect the "state-of-the-art" for serving persons disabled by autism. This should include assessments of client in nonsheltered settings, elimination of exclusions in the evaluating process, removal of time limitations for services, provision of monitors for as long as client requires this assistance.

B. Enclave Model

Persons disabled by autism should be assured of multi-site, small groups (three or fewer) or individual placements. Agencies must be aware that other workers inhibit independence.

C. Supportive Employment Model

Funding problems can be overcome through educating parents, professionals, legislators, and public. Preservice and inservice training need to be developed and implemented throughout the country. Dissemination barriers may be overcome through public education of professionals, agency personnel, parents, legislators, and the public.

V. Future

Activities and changes desired within the next two years:

1. Autism should be mentioned in the DVR regulations as a severe handicap.
2. Demonstration projects should be conducted with grants from the Office of Education, NIHR, DD, and/or RSA.
3. Include autism as a priority population for DOE RFP's on grants such as the Transitional grants for school to work.
4. Training and personnel preparation grants and projects should identify autism as a priority targeted group.
5. A national meeting should be held within a two-year timeline to evaluate the outcome and implementation of recommendations from the Conference.
6. Within three months, the proceedings of this conference should be published.

Group III

Adult Service Systems

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Present Status

In order to be competitively employed, or even to have the chance for competitive employment, persons with autism must first be able to live in the community. Yet persons with autism have been perceived as too severe, too hard-to-manage and too different to fit into the existing community service system. Families seeking help and relief from care have received few supports, and then only marginal or even inappropriate services. Society's inclination to reject its members with severe disabilities has served to promote continued placement in isolated and segregated institutions. To support persons with autism and their families in the community and allow them real opportunities to become full members of the community with the right to work and to use their individual skills to their fullest capacity, we must educate the service system and its governing agencies not only to the needs of persons with autism, but to their strengths and unrecognized competencies. Without adequate and appropriate supports and services, these competencies will continue to go unrecognized.

Barriers to Services

Existing inadequacies are derived from community and professional attitudes, inappropriate and marginal services, limited resources and funding, and a lack of clear commitment to supporting persons with autism.

Myths and Attitudes

In order to gain recognition for the needs of the population of persons with autism, advocates have frequently stressed the deficits and differences in the expectation that support and funding would follow as the response to some real and drammatic stories. Instead they inadvertently promoted social attitudes and misunderstandings which lead to effective exclusion from the community. These ideas are maintained by such myths as:

1. **"Persons with autism prefer to be alone."** This myth has its origin in the substantial difficulties of persons with autism to communicate and interact socially with people around them, and has been maintained through the assumption that the disability reflects the intention of the person. Such misconceptions have nationalized the exclusion of persons with autism. Similar assumptions toward this population are that "they are unaware" and "they do not wish to communicate."

2. **"Meeting their needs is very costly."** This misconception has in fact led to the development of expensive segregated programs which frequently take persons out of their natural families and away from their communities. In this situation they are provided "round the clock" services with high staff ratios in settings where there are few meaningful opportunities to learn the common tasks of everyday living. Under the guise of meeting their needs, such artificial and restrictive groupings have done little to promote skills for community living and have exacerbated their difficulties in communication and social skills.

3. **"They are without feelings."** This myth which has its origin in the person's difficulty in using language expressively has not only allowed but even condoned and supported extreme and extraordinary professional practices of punishment, ineffective and detrimental uses of high-risk medications, and institutions.

4. **"Parents have caused or at least promoted the problems of their children with autism."** The etiology of autism was first considered to be a result of deficient parenting. Although current evidence clearly points to the biological nature of the causes of autism, myths die slowly and the suspicion of parental inadequacy lingers. Even when there is clear understanding that autism is not psychogenic, parents can still be viewed as part of the problem, i.e., they can not effectively teach or manage their children. On the other hand professional "failure" to effectively teach and manage persons with autism is excused by blaming the victims, both parents and children, for their inability to benefit from professional advice and direction. The blaming process contributes to the justification of social neglect of families and individuals by agencies and individual providers of services.

Inadequate Services and Supports

The array of community supports and services generally available to persons with other developmental disabilities is effectively denied to persons with autism. For the few persons who manage to gain access to existing services, it is made clear that their acceptance into programs is provisional and tenuous, and that expectations of success are minimal.

1. **Day Programs. Sheltered workshops,** day activity programs and day habilitation programs all tend to exclude persons with autism. The reasons given are the problem behaviors, the need for one-to-one staffing, the need for expensive consultation with "experts" in autism and an underlying belief that persons with autism can't learn to be productive. Sometimes families and advocates are advised, "If the behaviors can be brought under control, then we might reconsider the application." This response offers little hope since there are no services to help bring the behaviors "under control"; and without service the person with autism will tend to deteriorate.

   There is a presumption that sheltered workshops lead to employment opportunities, although there is little evidence to support the movement to competitive employment. However, the family views the exclusion from sheltered workshops as meaning their member with autism will never be capable of employment.

Day activity programs are focused on non-vocational or prevocational skills. They are set up to serve persons with more severe handicaps; yet they also exclude persons with autism for the reasons noted above.

Day habilitation programs were developed to serve persons whose needs were not being met in day activity programs. Enriched services through higher staff ratios and extensive involvement of medical and allied health professionals were the next solution offered. These, too, deny services to many persons with autism for the same old reasons.

The message received by families, other primary caregivers and advocates is that "your people are hopeless, helpless and don't belong in the community."

2. **Family Support Services.** For parents who try to keep their member with autism within the family, there are few services to provide the supports they need in kind, quality and amount. Needed support includes respite care, parent training, case management, counseling cash subsidies, and transportation. Perhaps the most important and the one that clearly recognizes the parents' efforts and contributions is respite care. There are, however, difficulties in finding a respite worker adequately trained and supported who is willing to provide service to the adolescent or adult with autism. Respite settings outside the home may also lack adequate expertise and back-up for the respite provider. Parents can find the search for intermittent respite care as frustrating and exhausting as the search for more continuous services.

   Parents who want to learn more effective home teaching methods may only find programs which, particularly for persons with autism, tend to emphasize getting the person under control and then teaching skills at a later time. Parents may resist a model of training which focuses on compliance out of a common-sense knowledge that they, the aging parents, are no physical match for their young adult children who may react to command with anger and frustration. Counseling tends to focus on the deficit model of parenting and/or to question parents' motivation in keeping their son or daughter at home once the professionals have recommended institutional placement. Lack of transportation or skilled transportation personnel can threaten to terminate already tenuous program placements for the "lucky few." Cash subsidies which are being set into place in some states for families of persons with severe handicaps can help to alleviate some of the financial drain on families, but they cannot buy services that are not available to persons with autism; nor can case management be effective when programs deny access to persons with autism and their families.

3. **Community Residential Alternatives.** When the family can no longer cope with the person with autism, the few community programs available tend to group persons with autism into autistic community residences. In some situations they are placed in isolated autistic farms thus perpetuating and even exacerbating the earlier feelings of social exclusion the person may have experienced in his/her family through social neglect by the responsible agencies.

Even foster families who are often eligible for more services and who may be more socially acceptable to agencies (since they did not produce the person with autism) have similar difficulties in accessing services.

Community residential programs serving other persons with developmental disabilities generally do not view persons with autism as appropriate clients. Like the other services described above they tend to focus on the difference and difficulties without seeing the person and his/her potential strengths. Without a place to live in the community, the person with autism is institution-bound. Based on past experience, the probability of persons with autism leaving the institution to return to the community is low, indeed.

4. **Education.** The one mandated service available to persons with autism, education, tends to isolate them from their non-handicapped peers and to provide them with few learning opportunities to prepare them for meaningful work and living in the community. They are placed in segregated classrooms and even segregated buildings, driven miles from home to some segregated programs, or placed in private or public institutuional environments as the appropriate educational "solution." Emphasis is generally placed on compliance training using artificial tasks in artificial settings. If any assessment or generalization of skills in natural contexts is done, the student is likely to fail for lack of experience and direct teaching in community environments. The failure is presumed to be further evidence of the student's inability to benefit from or to perform in the community. Opportunities for learning vocational skills are few; pre-vocational is the eternal mode; and the result is that the person is seen as capable of only the most rudimentary and probably unmarketable skills. Educated in isolation, these people will continue to function in this manner because they lack the social and job skills that would support their presence in the community.

5. **Lack of Agency Commitment.** Like the education agencies, other state and local agencies focus on the difference and difficulties instead of on the person. Agencies may be willing to purchase occasional isolated and costly out-of-community placements for persons with autism. They point to this as evidence of their good faith efforts to serve this population. However, this action on their part merely bolsters their abiding belief that serving persons with autism is an expensive and difficult proposition.

   They may ignore families' early requests for supports. Later when they do provide help, it is provided in inadequate amounts and through inappropriate services and poorly trained providers. The failure of the agencies to provide the needed supports serves to reaffirm their conviction that persons with autism can't live in the community.

   Agencies do little to educate themselves about the growing body of knowledge of effective education and training strategies for working with persons with autism. Training, if any, is based on the same old myths and assumptions that have kept people with

> autism out of the community. They defend their actions, or inaction, by using these same old attitudes and assumptions. They may point to the person with autism they are maintaining in a private institution at a cost of $50,000 or more as evidence of their commitment to the population. However, they are reluctant to infuse money into a community service system of supports and training which would better meet the needs of their clients with autism and their families.

These then are the obstacles to community service, presence and participation for persons with autism and their families. These obstacles are rooted in myths and misconceptions based on earlier inaccurate assumptions which have fostered and supported the isolation of persons with autism from the mainstream of community and family life.

An Appropriate Community System of Services and Supports

Everyone should be able to live in a family-scale home within the home community. Whenever possible the choice of remaining in the natural home must be provided. Programs to support families through adequate and appropriate services including cash payments should be the first response of the human services system. The involvement of family or individuals labeled as autistic is not a replaceable component of quality service delivery. No matter how caring and responsible the professional service providers may be, the perspective, concern and balance provided by the family and significant others is invaluable to the long-term welfare of individuals labeled as autistic.

A New Framework and Commitment.

A supportive community system views persons with autism as individuals rather than a class of here-to-fore different and difficult clients. Rather than ask, "Can we keep the autistic person in the community?", the new framework requires that we ask "What will it take to support and keep this person who happens to be labeled autistic in his home community and with his family?" Rather than ask "if", the service system can now focus on the "how."

To appropriately meet the needs of persons with autism, long-term, individually designed and well planned interventions and support services are usually required. In addition, service providers require the adoption of new ideas, practices and training which at the outset will necessitate the infusion of new funds designated to meet the needs of persons with autism. However, interventions done before individuals and families are in crisis are usually less costly and more effective. Money must be designated for supporting community integration rather than isolation.

The new framework requires a fresh look at persons with autism, i.e., recognition of their efforts to communicate and interact, an honest estimate of their skills and strengths, an appreciation of their families' contributions and sacrifices, and an acknowledgement that the families and their members with autism are doing the best they can under trying conditions, many of which are the result of agency neglect. This new understanding on the part of human service professionals should generate a respect for the persons involved and a commitment to meeting their daily and longterm basic needs.

Supports to Families

With appropriate and adequate supports, families can remain healthy, productive and unified for extended periods. They know their needs and these include:

- respite care, in the amounts and settings families request;

- training, to meet their needs for home teaching and for working with human services professionals;
- financial support, for the extraordinary expenses of caring for a person with autism;
- counseling, for those parents who request it and in the form they feel they need;
- recreational opportunities with community supports to enable the person with autism to participate in the community without the constant presence of the parents; and
- other support services as designated by individual families according to their perceptions of their needs.

Supported families will have more energy and time to maintain their commitment to their family members with autism. The benefit for persons with autism is that they will have more opportunities for community experience and the support and involvement of parents and other family members who are energized and realistically optimistic about the future of their sons and daughters with autism.

Education

For education to benefit persons with autism it is essential to use evaluation/assessments, curriculum and instructional methods appropriate to the present and future needs of students with autism. **Procedures used to assess** the skills of persons with autism need to be much more practical and rooted in real settings. Instead of the traditional forms of assessment and evaluation in which the students were perceived as failures, the focus should be on assessing what skills are needed by the student to function within community living, working and recreational environments. Discrepancy measures of the required skills and the person's current levels of performance can be the basis of the development of age-appropriate and community-based curriculum. Assessment procedures require the involvement of significant others including the student's family as well as a willingness to search out the special skills and talents the student with autism may possess.

Curriculum

Curriculum must be referenced to teaching community skills to prepare students to function in the environments they should experience upon graduation, i.e., skills such as doing laundry, crossing streets, using public transportation, interacting with store clerks, using community recreational facilities, etc. Training must take place in multiple community settings for increasing and significant portions of the school day. As the student ages, more and more time must be given over to work-related activities. Work-related activities should take advantage of the student's interests and special skills.

Instructional Methods

Instructional methods must be more direct, have real intensity and skill, and must be non-punitive. The field of autism has a shameful history in the use of coercion, punishment and aversive procedures. Other more positive alternatives are available and educators must put the negative "education by elimination" approaches behind them.

Educators who use positive and functional means to educate persons with autism will find greater satisfaction in working with their students, and are likely to elevate future expectations for their students with autism.

Work Training Opportunities

Since existing pre-vocational programs tend to exclude persons with autism, minimal effort should be expended on gaining entry for clients with autism to those programs. Job advocates, job trainers and other forms of supported employment may offer more hope and satisfction to persons with autism. If V.R. workers can support them through funding and staff placements in job settings (after a careful assessment in a real work setting), workers with autism can prove to be productive employees. Some of the traits inherent in autism may in fact enhance the worker's performance if appropriate sampling and matching of clients' skills and interests has preceded the placement and if adequate support is available as needed by the employer and client-employee.

Community Residential Alternatives

When it becomes necessary to seek another living arrangement outside of the family home, a small residential alternative must be considered. These include an array of supervised living arrangements such as foster homes, adult family homes, supervised and staffed apartment living, and home sharing. Small group homes can serve as either a short-term training setting to prepare individuals for more independent living or as a long-term residence. In general it is unwise for all residents within a home to have the same or similar disabilities and/or diagnoses. The balance of needs and skills found within a more heterogeneous setting allows for a more individualized and positive experience. Movement within the person's natural community allows the persons to continue close contact with their families, friends and interested others. Long distance, isolating placements disrupt people's lives, and many impact not only on individuals' productivity and life-satisfaction, but may interfere with the acquisition of further skills.

An appropriate community service system for persons with autism rests first upon a clear and unwavering commitment to serve clients with challenging behaviors. Each person must be considered in the development of individually designed services including long-term and flexible supports as needed. Additionally, adequate funding and training in new perspectives and techniques is essential to the development of a cadre of human service professionals who can be effective in supporting persons with autism in the community.

Strategies for Success

To provide such long-term services, a fundamental shift in human services must be accomplished. Resources must be available for small homes and within communities rather than large institutional settings. Individualized supported employment must be provided in regular workplaces rather than work activity centers for large numbers of individuals with severe disabilities. Provisions for person-centered, case management rather than infrequent, high case-load, superficial tracking must be included in the system. To begin to effect this fundamental shift, a variety of activities must be set in motion. The task is not as difficult as it seems. We do have effective models which, although few in number, are successfully integrating persons with autism into the community service system in an array of human services and in competitive employment. Strategies for developing a full set of services in every state include the following:

Public Information

Many people will need to be given accurate information about persons with autism, their needs and their abilities. The general public should be aware of what autism is and is not. Parents should be informed of the new framework for persons with autism. Key people for receiving accurate information are agency personnel (both administrators and those that provide direct services) and legislators at local, state and national levels. Trainers of teachers and other human service professionals should be the target of new information and methods of instruction as well as the service providers who return for continuing education.

The methods of disseminating information are as diverse as the groups who need to be informed. Organizations like TASH and NSAC can spread the word among their memberships, legislators, and agency officials. They also should make efforts to reach the general public as well as other advocacy organizations concerned with other persons with severe disabilities. Professional organizations including TASH can inform those in the service delivery system of new approaches that are available and why they are so desperately needed; they can influence the trainers of professionals to modify their curricula to include the new and more effective methods. NSAC can inform its parent members especially that there is hope for their children with autism, and that isolation and institutions need no longer be the promised end.

Information should be disseminated both verbally and visually through journal and newspaper articles, popular magazines, new textbooks and various publications of organizations who share concerns about persons with autism. Effective visual dissemination could use pictures, videotapes and films of persons with autism who are making it in the community, thus allowing our persons with autism to participate in self advocacy, a visual self advocacy which could be very powerful. We need to share the success stories of persons with autism if our information is to be received and believed. An improved image of persons with autism will go far toward influencing those who have the power to fund systems. Parents have a great deal of power they should use to reach and influence elected officials who can fund a responsive sevice system. They need to say "I want something more for my son (or daughter) than the service system is giving them now."

Funding

In order to develop a responsive and effective service system, new sources of money must be targeted for persons with autism. This money should be used for technical assistance to existing programs presently denying services to persons with autism, demonstration grants to encourage the development of new services and supports (including community support teams), training grants to improve curricula (medical, speech and language, rehabilitation, etc.) and special grants fostering the growth of parent professional partnerships.

Training

Training is usually contingent on funding which is needed to develop new standards of training for the array of human service professionals. Yet information in journals and at conferences can begin even now to impact on the quality of training. Training must be expansive enough to reach down to the levels of direct care workers who may be confused by characteristics of certain individuals with autism and by the array of myths and misconceptions they receive from the supervising professionals. With a minimum of accurate information and support they may be the most easily reached and retrained because of their frequent contact with the person. New training at all levels is essential to growth of a new and responsive system. If there is to be substantial, long-term change, such training must be adequately funded.

Legislation

New funding and eligibility for current funding comes from legislation or from the pressure of legislators upon public agencies. Funding, such as that proposed in the Community and Family Living Amendment would promote and support the kind of responsive and productive service system discussed here. Legislators must be informed in order to draft legislation that includes persons with autism in existing programs and to expand community services for all persons with severe handicaps.

The above strategies will be effective if all strategies are used concurrently. Information and attitude change give reason to increased funding; and funding is often given in response to an informed public. Training and model projects follow funding. For these strategies to be effective, there is a need for collaboration among parents, professionals, advocates and others interested in appropriate community systems for persons with autism.

Measuring Effectiveness

Given the paucity of services to persons with autism and the low incidence of persons with autism who remain in the community, the measurement of change is perhaps the easiest charge to the agencies. Any increase in the number of clients with autism served in the community will show a shift in policy. For the VR agencies, the question is "how many persons with autism have we included in our service system?"; for agencies which fund institutions, a more careful tally will be necessary. This will be true in the human service agencies such as state Mental Health (or Hygiene), Mental Retardation, Developmental Disabilities, Social Services and Education agencies. For education, scrutiny will be complicated by the fact that persons with autism can be segregated within community school settings. Yet all of these placements have clear physical dimensions which are easily measured. The number of new state plans will be a significant measure.

On the Federal level, the kinds of legislation and legislative funding will indicate the level of commitment to community services for persons with autism. The number of projects funded for training, demonstration and research in better service to persons with autism can be counted as well as the amounts of funding.

Finally, parents can be asked, "Is your son or daughter at home or elsewhere in your community, and are your needs being met?" When the answer is "Yes, yes;", we will be counting another success of a system which is beginning to respond to the human needs of individuals with autism and their families.

Group IV

Issues in Rehabilitation Personnel Preparation Regarding Autism

Committee Members

Anne Donnellan Gary Mesibov
Gary Lavigna

Present Status

Presently, there are no known systematic training efforts in the field of vocational rehabilitation designed to provide information about people with autism. Pre-service, university-based training efforts focus on counseling skills with little emphasis or applicability to chronic developmental problems such as autism. Although there have been sporadic in-service training efforts, these have been scattered throughout the country and have rarely been a part of any ongoing, systematic training effort. Consequently, service providers within the vocational rehabilitation field are ill equipped to deal with this most challenging population.

Barriers

There are many barriers to providing training to VR personnel serving individuals with autism including:

1. Autism is a low incidence disability, representing a small percentage of those served by VR. Consequently, many counselors may have only 1 or 2 autistic clients every 3-4 years, making training less meaningful to them. University training programs are geared toward other populations.
2. Aspects of the VR system do not adequately meet the needs of autistic clients. Therefore, training efforts might be compromised because they do not fit ongoing practice. Examples include the evaluation process and emphasis on unsupported competitive employment as the only way to achieve case closures.
3. Financial limitations in using training funds for a low incidence disorder.
4. Lack of people skilled in autism and the vocational rehabilitation system to provide training.
5. Lack of appropriate training materials.
6. Lack of appropriate models of vocational possiblities for people with autism.
7. High personnel turn over.

8. Child emphasis in autism information and training to date.
9. Lack of awareness of the need for this training by state-level officials and University faculties.
10. Problem of identifying autistic clients in a VR caseload and recognizing their special needs.

Training and Dissemination

The following are strategies for meeting our training and dissemination goals and objectives:

1. To establish a rehabilitation research and training center for autism within two years.
2. To develop and provide an awareness presentation, within two years to the following groups:
    - a. National Association of Rehabilitation Facilities.
    - b. Council of State Administrators in Vocational Rehabilitation.
    - c. President's Committee on Employment for the Handicapped.
    - d. National Council on Rehabilitation Education.
    - e. American Rehabilitation Counselors Association.
    - f. Division 22 of the APA.
3. To develop within two years a plan for widespread training and dissemination utilizing training teams in each of the ten Regional Centers for Continuing Education, and to have these combined regional centers complete 25 training program cycles within five years.
4. To have, within two years, a monograph of the Institute on Rehabilitation Issues address the topic of autism.
5. To propose within 6 months an article which can be edited for publication in all relevant trade publications and non-association bulletins on the topic of autism and vocational rehabilitation, and arranging for the publication of this article in at least four places within two years.
6. To disseminate the National Conference on Autism Proceedings to such groups as in No. 2 above plus:
    - a. Regional Offices of VR.
    - b. State Offices of VR.
    - c. Research Utilization Groups
    - d. NSAC Chapters (with cover letter)
    - e. NSAC/NPT state level training teams
    - f. NSAC book store.
7. To develop public service announcements within 6 months.
8. To develop within two years state level planning committees of parents and agency representatives to address training and needs.

TRAINING GOALS AND OBJECTIVES

State Departments of Vocational Rehabilitation

Immediate Awareness

Attitude Readjustment

Non/less-stigmatizing punitive behavior management strategies

Characteristics of autism (similarities & differences with others)

Assessment/evaluation

Access existing mechanism, existing systems, (e.g., financial resources)

Working with related services & agencies (advocacy)

Job development

Institutional change strategy

Working with families

Staff recruitment, training, maintenance, supervision, support

Program evaluation and quality control

Curriculum development

Longitudinal Implement

Access existing mechanisms, existing systems (e.g., financial resources)

Working with related services & agencies (advocacy)

Job development

Institutuional change strategy

Staff recruitment, training, maintenance, supervision, support

Program evaluation and quality control

Resource

Conference NSAC-NPT

TEACCH

TASH

NSAC

Association for Applied Behavior Analysis/Association for Advancement of Behavior Therapy

Contact People

CEC

University Training Personnel

Immediate Awareness	*Longitudinal Implement*	*Resource*
Attitude Readjustment	Attitude Readjustment	List of Universities doing training
Non/less-stigmatizing punitive behavior management strategies	Non/less-stigmatizing punitive behavior management strategies	Wisconsin
Characteristics of autism (similarities & differences with others)	Characteristics of autism (similarities & differences with others)	UNC San Francisco State
Instructional techniques	Instructional techniques	Syllabus
Assessment/evaluation	Assessment/evaluation	
Access existing mechanism, existing systems, (e.g., financial resources)	Access existing mechanism, existing systems, (e.g., financial resources)	
Working with related services & agencies (advocacy)	Working with related services & agencies (advocacy)	
Job development	Job development	
Institutional change strategy	Institutional change strategy	
Working with families	Working with families	
Staff recruitment, training, maintenance, supervision, support	Staff recruitment, training, maintenance, supervision, support	
Program evaluation and quality control	Program evaluation and quality control	
Curriculum development	Curriculum development	

Rehabilitation Counselors

Immediate Awareness	*Longitudinal Implement*	*Resource*
Attitude Readjustment	Attitude Readjustment	Regional & National Conference of Rehabilitation Agencies
Non/less-stigmatizing punitive behavior management strategies		
Characteristics of autism (similarities & differences with others)		San Francisco State
Instructional techniques		Syllabus
Assessment/evaluation	Assessment/evaluation	
Access existing mechanism, existing systems, (e.g., financial resources)	Access existing mechanism, existing systems, (e.g., financial resources)	
Working with related services & agencies (advocacy)	Working with related services & agencies (advocacy)	
Job development	Job development	
Institutional change strategy	Institutional change strategy	
Working with families	Working with families	
Staff recruitment, training, maintenance, supervision, support		
Program evaluation and quality control	Program evaluation and quality control	
Curriculum development		

Client Evaluators

Program

Facility Staff

Immediate Awareness	*Longitudinal Implement*	*Resource*
Attitude Readjustment	Attitude Readjustment	
Non/less-stigmatizing punitive behavior management strategies	Non/less-stigmatizing punitive behavior management strategies	
Characteristics of autism (similarities & differences with others)	Characteristics of autism (similarities & differences with others)	
Instructional techniques	Instructional techniques	
Assessment/evaluation	Assessment/evaluation	
Access existing mechanism, existing systems, (e.g., financial resources)		
Working with related services & agencies (advocacy)	Working with related services & agencies (advocacy)	
Job development	Job development	
Institutional change strategy		
Working with families		
Staff recruitment, training, maintenance, supervision, support		
Program evaluation and quality control		
Curriculum development	Curriculum development	

Contractual

Immediate Awareness	*Longitudinal Implement*	*Resource*
Attitude Readjustment	Attitude Readjustment	Rehabilitation
Non/less-stigmatizing punitive behavior management strategies	Non/less-stigmatizing punitive behavior management strategies	Develop
Characteristics of autism (similarities & differences with others)	Characteristics of autism (similarities & differences with others)	Monograph on Non-Aversives
Instructional techniques	Instructional techniques	
Assessment/evaluation	Assessment/evaluation	
Access existing mechanism, existing systems, (e.g., financial resources)	Access existing mechanism, existing systems, (e.g., financial resources)	
Working with related services & agencies (advocacy)	Working with related services & agencies (advocacy)	
Job development	Job development	
Institutional change strategy	Institutional change strategy	
Working with families	Working with families	
Staff recruitment, training, maintenance, supervision, support	Staff recruitment, training, maintenance, supervision, support	
Program evaluation and quality control	Program evaluation and quality control	
Curriculum development	Curriculum development	

Trainers/Adjustment Specialists
Job Coaches

Immediate Awareness	*Longitudinal Implement*	*Resource*
Attitude Readjustment	Attitude Readjustment	Rehab brief
Non/less-stigmatizing punitive behavior management strategies	Non/less-stigmatizing punitive behavior management strategies	Community training
Characteristics of autism (similarities & differences with others)	Characteristics of autism (similarities & differences with others)	
Instructional techniques	Instructional techniques	
Assessment/evaluation	Assessment/evaluation	
Access existing mechanism, existing systems, (e.g., financial resources)		
Working with related services & agencies (advocacy)	Working with related services & agencies (advocacy)	
Job development	Job development	
Institutional change strategy		
Working with families	Working with families	
Staff recruitment, training, maintenance, supervision, support		
Program evaluation and quality control		
Curriculum development	Curriculum development	

Families/Care-Givers

Immediate Awareness	***Longitudinal Implement***	***Resource***
Attitude Readjustment	Attitude Readjustment	Give them state/ director list
Non/less-stigmatizing punitive behavior management strategies	Non/less-stigmatizing punitive behavior management strategies	Parent network
Characteristics of autism (similarities & differences with others)	Characteristics of autism (similarities & differences with others)	
Instructional techniques	Instructional techniques	
Assessment/evaluation	Assessment/evaluation	
Access existing mechanism, existing systems, (e.g., financial resources)	Access existing mechanism, existing systems, (e.g., financial resources)	
Working with related services & agencies (advocacy)	Working with related services & agencies (advocacy)	
Job development	Job development	
Institutional change strategy	Institutional change strategy	
Working with families	Working with families	
Staff recruitment, training, maintenance, supervision, support	Staff recruitment, training, maintenance, supervision, support	
Program evaluation and quality control	Program evaluation and quality control	
Curriculum development	Curriculum development	

Rehabilitation Personnel

Immediate Awareness

- Attitude Readjustment
- Non/less-stigmatizing punitive behavior management strategies
- Characteristics of autism (similarities & differences with others)
- Instructional techniques
- Assessment/evaluation
- Access existing mechanism, existing systems, (e.g., financial resources)
- Working with related services & agencies (advocacy)
- Job development
- Institutional change strategy
- Working with families
- Staff recruitment, training, maintenance, supervision, support
- Program evaluation and quality control
- Curriculum development

Longitudinal Implement

Resource

- Distribute monography to CSSO
- Vocational Education
- Special Education
- Training

Employers/Potential Employers

Immediate Awareness	*Longitudinal Implement*	*Resource*
Attitude Readjustment	Access existing mechanism, existing systems, (e.g., financial resources)	Letters from employers of persons with severe handicaps
Non/less-stigmatizing punitive behavior management strategies		
Characteristics of autism (similarities & differences with others)		
Access existing mechanism, existing systems, (e.g., financial resources)		
Job development		

General Public

Immediate Awareness	*Longitudinal Implement*	*Resource*
Attitude Readjustment		PSA
Characteristics of autism (similarities & differences with others)		One-half hour of film
		Distribution of brochure

Autism Services:
A Blueprint for the Future

Douglas Fenderson
Public Health and Research Coordinator
University of Minnesota Medical School
Minneapolis, Minnesota

Concluding Comments

Douglas Fenderson

In December 1982, as the new Director of the National Institute of Handicapped Research (NIHR), I found some unexpected language in our appropriation report. It called for NIHR to initiate a training program for rehabilitation counselors throughout the country with a goal of including persons with autism in their service programs.

In attempting to understand congressional intent, I checked the prevalence and incidence data and spoke with colleagues in the Rehabilitation Services Administration and special education programs. I learned that vocational rehabilitation had no specific code for autism. In special education, many of these children are never identified as autistic, and even if they were, it probably did not lead to services uniquely appropriate to their needs.

Within a few weeks, NSAC leaders who had worked so effectively for this appropriations report language appeared in my office. We agreed that before attempting to train all rehabilitation workers on how to serve clients with autism, we needed something like a rehabilitation blueprint to guide the effort. This meeting is a result of the subsequent discussions. In the meantime, however, two of the three new support programs of NIHR, initiated during my tenure—the Switzer Research Fellowship Program and the Investigator Initiated Research Program—have begun to support much needed study of the rehabilitation service need and opportunities of this group.

The premise of the appropriations language and this meeting is that much more could be done to enhance the personal and productive capacities of persons with autism if service providers were aware of the need and potential of this group and were committed to including them in their programs and plans.

Several blueprints have already been presented at this conference. Dr. Martha Denckla presented an outstanding paper on the needs for basic research in autism. Dr. Anne Donnellan summarized the collected literature on rehabilitation of persons with autism and included her well-informed views of the needs for applied research. Frank Laski presented a thoughtful blueprint regarding public policy issues. Dr. Gary Lavigna summarized for us a "transportable" version of the Maryland model. Marjorie DeBlaay created for us a framework for a blueprint. Finally, the excellent reports from each of the four groups serve to fill in the details.

The history of rehabilitation is a continuing redefinition of the unacceptable. Over the past 15 years, we have seen extensive legislation on behalf of the civil rights of disabled persons. The major pressure for these impressive achievements has come from disabled persons, themselves, and their advocates. The role of professionals in rehabilitation and special education has been relatively minor. These major legislative initiatives are listed in an article by Gerbin DeJong in **Scientific American**, June 1983, entitled "Disability and Public Policy." These changes in law and program tend to follow rather than lead public belief and will. Thus, the continuing redefinition of the unacceptable for disabled individuals has been largely in the hands of those most aware of the implications and opportunities, namely the disabled individuals themselves.

An interesting concept emerged in our discussion regarding autism as a classic model for rehabilitation services. In medical rehabilitation, teaching programs have used such conditions as paraplegia, stroke and amputation as teaching models, since they convey the broad range of medical and community services required to re-establish optimum levels of function. In a similar sense, autism may be seen as such a model in the area of developmental disabilities. If community-based service providers can be successful in achieving educational and habilitative goals with this group, all other such problems of developmental disabilities may be seen in clearer perspective.

The following elements of a provisional blueprint were outlined in the discussion:

1. Autism is now identified as a specific, codable condition within the rehabilitation and educational programs.

2. Appropriate protocols for diagnosis and assessment in relation to special education, community and vocational rehabilitation service programs need to be refined and communicated to the respective audiences, including special education leaders, state DD councils, state directors of vocational rehabilitation and other community service programs. Such assessments together with the newly established code should lead to descriptive numerical data which are essential to subsequent planning.

3. Vocational rehabilitation services might be facilitated if a model "minimum essential definition of eligibility," characterizing both the nature of the handicap as well as indications of feasibility for services were similary established and communicated.

4. Orientation and training at the federal, regional center, state, district office and DD council-levels are of timely and compelling importance. Contracts for the development of such orientation and training materials need to be developed and negotiated with NSAC.

5. Models of successful practices need to be confirmed and communicated. Several speakers emphasized that paper and pencil and work-sample assessment procedures lack predictive validity. Professional custom and practice has generally led to withholding of appropriate services based on limited information with regard to appropriate means for assessment and prediction of "state-of-the art" outcomes. It may be useful to point out that client-assistance programs (CAP) are part of the vocational rehabilitation programs throughout the country. Unfavorable determinations that are not based on state-of-the art standards may thus be appealed through the CAPs. The respective federal agencies share the responsibility with NASC in communicating these models, and in confirming them by replicating the most promising versions sufficiently so that leaders in this field may speak with authority regarding the generalizability of the models.

6. The elements of a federal-level action agenda have been identified during this conference. These include the passage of the community living amendment and the allocation of financial resources in relation to the individual needs rather than primarily simply institutional plans. Continued and increased flexibility with regard to medicaid and medicare health insurance are part of this agenda. The basic science agenda for NIH of which Dr. Denckla spoke, and the applied research agenda, consistent with the mission of NIHR, which Dr. Donnellan Refers to in her excellent paper are also pertinent.

7. A state agenda has also been suggested. This includes the concept of the coordination of services, the continuum of services, the mixing of agency funds in relation to individual rehabilitation goals and the establishment and communication of standard

assessment protocols more appropriate to prediction and demonstration of the higher levels of function that have now been established.

8. A private sector agenda has been suggested as well. Employers with experience in this area need to contribute letters attesting to their experience. Service club presentations can help to spread the word. Publications of the respective trade associations can open new opportunities for employment. NSAC must continue its effective role as a change agenda to bring pressure to bear on the impediments in both the public and private sectors and to continue to redefine the acceptable. Other specialized areas of private leadership include programs for socialization, leisure activities, therapeutic recreation, and the development of self-esteem. The continuation and expansion of family support networks is part of this private sector agenda as well.

9. Another action agenda has to do with some of the existing service systems whose operating assumptions tend to exclude this clientele. Specifically, sheltered workshops need to be confronted in terms of archaic notions of predictive validity of their assessment procedures. They need to be convinced to redefine their role and to augment their "product mix" to include the range of supported work options presented so convincingly in this meeting. The concept of pre-vocational seems to be a particularly troublesome one to confront. As two of our speakers have noted, "pre" means never for this group.

You have heard the old slogan, "vote early and vote often." This is our continuing challenge—to tell the success stories and to form broader coalitions with groups which share common concerns regarding community services, education, leisure activities, rehabilitation services and the like.

As we pursue these goals, we are faced with a dilemma regarding the impediments of attitudes both within the general public as well as the professional communities. How do attitudes change? Are attitudes not, in fact, an accommodation to new realities? We must concentrate on creating and communicating new realities. New attitudes will follow!

Appendixes

CSAAC Vocational Program

Autism Program Planning Committee

Conference Faculty

Conference Participants

Appendix A

CSAAC Vocational Program

Overview

Prepared by Patricia D. Juhrs

Community Services for Autistic Adults and Children (CSAAC) is a private, nonprofit organization. CSAAC operates a school, adult residential program and adult vocational program.

CSAAC initiated vocational services for adults disabled by autism in 1980. This program began out of an emergency need. At that time, CSAAC operated two group residences. When the men had been terminated from their day activity placements. Several of these men had already experienced expulsion from other sheltered placements in the area, due to behaviors related to their disability. The Maryland State Department of Health and Mental Hygiene, Mental Retardation Administration (MRDDA), funded CSAAC to develop day services for these adults to avoid institutionalization and remain in the CSAAC residential program.

The program we developed for these residents has expanded over the past years, but the model remains the same.

Work in companies in our communities is sought where the jobs are compatible with the strengths and needs of the client.

Counselors are hired and trained to implement specific instructional and behavioral programs in the industry sites and to teach the client specific work skills, social skills, travel to and from work, banking and other work related skills.

A psychologist, speech and language therapist, and other professionals are employed to design specific instructional programs, demonstrate programs and train counselors to implement the programs in the worksites. Client progress is monitored by all involved professionals.

Clients are paid by the companies for their work. Counselors are employees of CSAAC and are faded out as the client develops skills necessary for independence.

There are definite program as well as client advantages for the client to earn as much money as possible. There are definite program and counselor advantages for the client to become independent in travel, work, banking and other areas. Clients remain supervised as long as necessary and no time limits are set on achieving total independence.

Upon entry, clients are placed immediately in community worksites when compatible placements are available. A room in the CSAAC office is assigned for vocational testing and may be used during the job acquisition periods. But community training (i.e. community travel training, money skills and other "outside training activities" are primary for the client awaiting placement.)

If after trying different instructional approaches, the client is unsuccessful, we seek different work or a more compatible company.

All clients, regardless of their behavioral disorders, functioning levels or previous experiences are placed and trained in nonsheltered sites among nonhandicapped workers. The continuum model which focuses on movement from segregated to integrated environments is rejected in favor of a continuum of supportive services applied directly in the integrated work place. The severity of the client's disability is accomodated by provision of adequate supportive services including low staff ratios and additional professional services within the integrated, community work place.

The Vocational Program now serves 35 adults and is developing transition training sites for an additional eight school-aged (adolescent) students. Twelve (12) of the adults entered the program in 1980-1981, fourteen (14) entered in 1982-1983, nine (9) entered in 1980-1981, fourteen (14) entered in 1982-1983, nine (9) entered in 1984-1985 and two will enter in the late spring 1985 to make the total number served 37 by June 1985.

Not one client had a successful job history prior to entry. Most had unsucessful sheltered or day activity placements prior to entry. No one, prior to their entry into CSAAC, expected these clients to perform and be paid for meaningful work in private industry.

Fifteen (15) clients or 58% of the individuals who have been in the program for a minimum of one year have learned to travel to and from work without supervision. An additional six individuals are partially independent in use of public transportation to get to and from work. Over half of the clients, or nineteen individuals, earn wages of minimum wage or better. Two individuals are completely independent at work with drop-in supervision, and six individuals are having gradual reduction of supervision moving to partial supervision at this time.

The model has also been extremely successful in developing skills and relationships which may not have been formally measured by data collection. Clients have established relationships outside of parents, professionals, and other disabled people who traditionally are the client's primary social contacts. Through these relationships at work the individuals are viewed as valued coworkers rather than clients or children and the coworkers frequently act as unpaid, unsolicited advocates and role models.

The program has grown in the past years but the philosophy and beliefs remain constant...

- Persons with autism have the right to live and work in the community among nonhandicapped people.
- Pre means never—the continuum of services must be provided within the normal work environment with withdrawal of staff and supportive services as the client moves towards independence.
- Agressive, self injurious and other behaviors commonly associated with autism can be changed through nonpunative approaches, within nonsheltered community worksites.

Specific program information:

1. **Criteria for entry:** minimum of 21 years old; approved for funded placement by state Mental Retardation Developmental Disabilities Administration. Disabled by autism or exhibits autistic behaviors; priority goes to those in institutions or at risk of institutionalization.
2. **Staff ratio:** Staff ratio is dependent on the needs of the individual. A few individuals require 1:1 to prevent serious injury to self or others. Most require 1:2 or 1:3 for training. Staff ratios are determined by the Interdisciplinary Team.
3. **Testing and evaluation:** standardized testing and vocational evaluations are conducted upon entry into the program. Evaluations are conducted to meet accreditation standards, and other regulations and may be used to determine strengths. Specific criterion referenced data taken in actual nonsheltered work sites measuring production.and performance of specific job skills, travel

skills or other skills has proven to more accurately preduct needs, strengths, abilities and placement.

4. **Job placement:** Each client entering the program is placed as soon as a compatible site is located. There is no preparation period.

Matching placements and work with individual needs must take into account environmental needs of the individual—many unacceptable behaviors are condoned in certain environments; sometimes a behavior which has been labeled unacceptable (picking strings, twirling strings) may be a component of the job, i.e. twirling small wires in electronics plant.

5. **Compensation** - All private industry employers are expected to pay clients for work. Companies are assisted by CSAAC in applying for special worker certificates for compensation on the basis of productivity. Most opt to pay clients regular entry level wages. CSAAC assists employers to obtain tax credits. CSAAC counselors are paid by CSAAC. Government agencies do not have to pay for non-contracted work. Non-paying government placements have been used to gain paying government work.

6. **Timelines** - Counselors provide supervision and training both at the worksite and in travel training the individual as long as the Interdisciplinary Team determines these services are needed.

7. **The Interdisciplinary Team** is comprised of the client and all individuals providing services to the client. Supervisors from the company employing the client are also invited to the team meeting to report on the client's work performance. The Team convenes within 30 days of entry, reviews the comprehensive evaluation, makes placement decisions, staffing decisions, develops individual program goals and objectives and determines responsibility for implementation. Each goal and objective is reviewed monthly; data concerning behavioral and other specific priority objectives are analyzed and the Team is reconvened if major changes are recommended. Otherwise the Team reconvenes on an annual basis. Plans to reduce supervision are developed by the Team when the individual meets specific objectives.

Adult Client & Program Data

1985 Total Number of Adult Vocational Clients	37

Ages of Clients

21-25 years	**19**
26-30 years	**13**
30-40 years	**4**
40-45 years	**1**

Previous Placement Institution	19

IQ Ranges

Below 30	**9**
31 - 50	**6**
51 - 70	**7**
71 - 80	**6**
81 - 100	**4**
Above 100	**5**

Previous History of 140 Behavioral Disorders

Severe aggressive behavior	**20**
Severe self injurious behavior	**25**
Destructive behavior	**21**
Self stimulation	**37**
Previous history of use of major tranquilizers	**27**

Communication

Does not use speech to communicate	**8**
Uses single words or phrases to communicate	**9**
Uses fluent speech without applying social rules	**20**

Past-Present Worksites & Industries	**24**
Printing	4
Electronics	3
Packaging	2
Retail/Stockroom	3
Services-Library	2
Computer/related industries	2
Medical/laboratories	1
Recycling	2
Mailing	1
Equipment manufacturing	3
Clothing manufacturing	1

Number of worksites operating April 1985	**14**
Average number clients per site	**2.6**

Reasons for Worksite Change - Worksite Dropped

Company relocates out of area, sites too far away	5
Business losses resulting in company-wide layoffs, (lack of work or client movement)	4
Client problems (clients unable to develop skills, behavior problems; etc.)	1

Program Costs	**1980**	**1985**
Number of Clients	12	37
Annual Gross Cost Per Client (less client contribution)	$12,500	$11,627
State MRDDA Share per Client	$12,500	$ 9,467
County Share	-0-	14%
Client Share	-0-	4%

* Optional voluntary contribution by client applied against supervision costs under S.S.I. IWRE or PFSS programs.

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